Fetal alcohol spectrum disorder in Canada: An interdisciplinary analysis of media content and stakeholder perspectives

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Abstract

Fetal alcohol spectrum disorder (FASD), a complex and controversial diagnosis thought to impact at least 1 in 100 Canadians, results from prenatal alcohol exposure. People with FASD report difficult circumstances and stigmatization, as do birth mothers and women who drink alcohol while pregnant. Given limited public knowledge about FASD in Canada, news media is one possible source of public information and misinformation. Consequently, given challenges posed by FASD and associated stigma, we conducted two studies on 1) media discourse about FASD in Canada; and 2) lived experiences of Canadian FASD stakeholders. The first study, a media content analysis of 286 Canadian print media articles published from 2002-2015, identified several consequential areas of ethical concern on science and health communication, portrayals of people with FASD, and social expectations borne by women and mothers. These included exaggerated Indigenous FASD prevalence, contradictory health advice for pregnant women, and accurate information lacking context. We also saw an overemphasis on connections between FASD and criminal behaviour, and messaging that held women alone responsible for a child's wellbeing. Building on this analysis, the second study, a multi-category focus group project with 63 participants in three stakeholder groups (i.e., people with FASD, caregivers, and professionals) across several Canadian urban centres, explored participant experiences, and reactions to and recommendations about news coverage and public discourse. Participants identified a range of stereotypes associated with FASD, alcohol, and pregnancy, as well as five overlapping and sometimes conflicting recommendations to shift and improve public discourse – hope, inclusion, fear, education, and community. This interdisciplinary research offers insight into such questions and suggests that more work is needed to understand the impact of different discursive and interventional strategies on many complex and intersecting stakeholder identities.

Résumé

Le trouble du spectre d’alcoolisation fœtale (TSAF), un diagnostic complexe et controversé qui toucherait au moins 1 Canadien sur 100, résulte d'une exposition prénatale à l'alcool. Les personnes avec du TSAF éprouvent des circonstances difficiles et de la stigmatisation, tout comme les mères biologiques et les femmes qui consomment de l'alcool pendant leurs grossesses. Étant donné les connaissances publiques limitées au sujet du TSAF au Canada, nous estimons que les médias sont une source publique possible d'information et de désinformation. Par conséquent, étant donné les défis posés par le TSAF et la stigmatisation qui y est associée, nous avons mené deux études portant sur le discours des médias sur le TSAF au Canada et les expériences vécues des partis prenants canadiens dans le domaine du TSAF. La première étude - une analyse du contenu médiatique de 286 articles de la presse écrite canadienne publiés entre 2002 et 2015 - nous a permis d'identifier plusieurs préoccupations éthiques concernant la communication scientifique et clinique, la représentation des personnes avec du TSAF et les attentes sociales portées par les femmes et les mères. Il s'agit notamment de la prévalence exagérée du TSAF chez les populations autochtones, de conseils de santé contradictoires pour les femmes enceintes et d'informations précises manquant de contexte. Nous avons également constaté que l'on met trop d'accent sur les liens entre le TSAF et le comportement criminel, et que les messages tiennent les femmes comme seules responsables du bien-être des enfants. S'appuyant sur cette analyse, la deuxième étude - un projet de groupe de discussion multi-catégories avec 63 participants comportant trois groupes de partis prenantes (c.-à-d., les personnes avec du TSAF, les aidants naturels et les professionnels de la santé.) dans plusieurs centres urbains canadiens - nous a mené à une exploration des expériences des participants, de leurs réactions et de leurs recommandations concernant le discours médiatique et public. Les participants ont identifié une gamme de stéréotypes associés au TSAF, à l'alcool et à la grossesse, ainsi que cinq recommandations pour modifier et améliorer le discours public - espoir, inclusion, peur, éducation et communauté. Ces recommandations se chevauchent et sont parfois contradictoires. Cette recherche interdisciplinaire offre un aperçu de ces questions et suggère que des travaux supplémentaires sont nécessaires pour comprendre l'impact des différentes stratégies discursives et interventionnelles sur les nombreuses identités complexes et entrecroisées des parties prenantes.

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Members of the neuroethics (now pragmatic health ethics) unit have all contributed to my academic and personal growth. Thank you, Victoria Saigle, Dearbhail Bracken-Roche, Natalie Zizzo, my first cohort of close graduate school friends. Thank you, Dr. Veljko Dubljevic, whose experience helped me build my knowledge base. Thank you, Dr. Matthew Sample, Dr. Claudia Barned, and Dr. Ariel Cascio, who arrived as others left, just in time to build new friendships, and whose presence and training in disciplines I knew nothing about helped shape my work and understanding of the world. Thank you, Ariane Quintal, for discussions about similar projects from similar neuroscience backgrounds. Thank you as well to everyone else in the Tea Crew, including Roxanne Caron, Jelena Poleksic, Corinne Lajoie, and Wren Boehlen.

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Pronoun use (I and We)

In my thesis, I have used the pronouns ‘I’ and ‘We’ (or ‘my’ and ‘our’) to refer to work undertaken by me alone or with the assistance of co-authors, respectively. The work completed, reported, and discussed in this dissertation is my own, though our research unit is a collaborative one involving the input and contribution of colleagues at different stages. For more information on co-author contributions, please see the “Contributions of Authors” section following this one.

Contribution of Authors

All co-authors and publishers granted permission for manuscripts to be included in my thesis.

Manuscript I: Stigmatisation, exaggeration, and contradiction: An analysis of scientific and clinical content in Canadian print media discourse about fetal alcohol spectrum disorder

Authors: John Aspler, Natalie Zizzo, Emily Bell, Nina Di Pietro, and Eric Racine

Contributions: In 2012, ER, EB, and NDP designed the initial project on FASD in Canadian news; NZ collected data and conducted preliminary content analysis; ER, NZ, and EB used a sample of 25 articles to develop a coding guide, which was systematically applied by NZ to the remainder of the sample. ER and NZ assessed intercoder reliability for each code and subcode across iterations, discarding six codes and five sub-codes with a percent agreement below 0.75. In 2013, JA updated and expanded the study sample (modifying inclusion and exclusion criteria), adjusted the coding guide (identifying new themes, collapsing old ones, reorganizing others), and conducted a more detailed analysis of the data, which ER reviewed – including another round of intercoder reliability testing. JA and ER identified two overall categories of themes (science and health themes; social themes), which structured this and the following manuscript. JA drafted the initial manuscript and revised subsequent versions, explored the literature on science and health communication, and deliberated on ethical challenges associated with science communication. Co-authors provided input on the outline and final drafts of the manuscript.

Manuscript II: Stereotyping and stigmatising disability: A content analysis of Canadian print news media about fetal alcohol spectrum disorder

Authors: John Aspler, Natalie Zizzo, Nina Di Pietro, and Eric Racine

Contributions: The data was collected and analyzed as described in Manuscript I. The focus of this paper (disability stereotypes in news media; disability studies) was identified and researched by JA, who drafted the initial manuscript and revised subsequent versions. ER, NZ, and NDP provided input on an outline, and the penultimate and final drafts prior to submission. ER provided additional feedback and guidance throughout the manuscript-writing process.

Manuscript III: "It's ignorant stereotypes": Key stakeholder perspectives on stereotypes associated with fetal alcohol spectrum disorder, alcohol, and pregnancy

Authors: John Aspler, Aline Bogossian, and Eric Racine

Contributions: JA and ER designed the project, including choosing the sample population, the method employed (focus group interviews), and the interview questions. JA and AB conducted the interviews, with JA asking questions and moderating, and AB taking notes and providing support to participants experiencing distress. JA analyzed the data with AB to construct the initial coding guide, and ER reviewing all stages of the analysis. JA drafted the initial manuscript and revised subsequent versions; AB and ER provided input on different versions.

Manuscript IV: Hope, Inclusion, Education, Community, and Fear: Stakeholder recommendations for public discourse about FASD, alcohol, and pregnancy

Authors: John Aspler, Aline Bogossian, and Eric Racine

Contributions: Data collected and analyzed, manuscript written as described in Manuscript III.

Book Chapter: *Making research more ethical for adults with FASD: A story of stakeholder engagement, accommodation, and inclusion* in M. Ariel Cascio and Eric Racine, (ed.) Research Involving Participants with Cognitive Disability and Difference: Ethics, Autonomy, Inclusion, and Innovation.

Author: John Aspler

Contributions: Personal reflections on methods in manuscripts III and IV. Written alone, with editorial comments from ER (thesis supervisor, book co-editor) and MAC (book co-editor).

Contribution to Original Knowledge

The research in my thesis makes a novel contribution to the understanding of both public discourse about FASD, alcohol, and pregnancy in Canada (Chapters 3 and 4) and the lived experiences of Canadian FASD stakeholders (Chapters 5, 6, and 7).

Prior to this work, while several news analyses had been conducted in other countries, to our knowledge, no one had comprehensively studied Canadian print news. Crucially, this analysis provides insight into the information Canadians may have been exposed to about FASD, alcohol, and pregnancy–information that could contribute to informing and misinforming public attitudes about people with FASD and women who consume alcohol while pregnant. To my knowledge, this news analysis was also the first to connect news coverage about FASD, alcohol, and pregnancy to common media stereotypes about people with disabilities (Chapter 4). While disability broadly is represented through both extreme positive and negative stereotypes (i.e., victim, hero, burden, villain), I found that stereotyped coverage of FASD was only negative.

In Chapter 5, I provide a first participant-described account of the stereotypes that might exist about FASD, alcohol, and pregnancy. While work has been done in Canada and globally to understand the experiences and views of different FASD stakeholder groups, those experiences neither appear to have often been brought into conversation using a multi-category focus group design nor have the people with FASD often been centred. Crucially, our work explores potential stigma associated with a diagnostic label like FASD, and the way it could impact many related stakeholder groups. Work on stigma, disability stereotypes, alcohol, pregnancy, and FASD is not new, but this work is some of the first to tie them together and reflect participant accounts. In Chapter 6, to my knowledge, this work is the first to conduct a news analysis and then to ask people with FASD about their reactions, and how that coverage and discourse could improve.

THESIS OVERVIEW

Research objectives

The studies and manuscripts reported in this thesis served a singular goal: To generate knowledge that can help improve the lives of key FASD-associated stakeholders. Toward that end, we aimed to generate knowledge about the media coverage and public portrayal of FASD, alcohol, and pregnancy, to explore associated stereotypes and stigma, and to engage stakeholders in research investigating their perspectives on media content about their lived experiences. We approached these concerns via the following research objectives and questions:

- *Objective 1:* To understand the kind of information presented to Canadians through news media about FASD, alcohol, and pregnancy
- *Objective 2:* To learn about the lived experiences and perspectives of Canadians with FASD and other key stakeholders
- *Objective 3:* To understand the views of key FASD stakeholders regarding Canadian media coverage of FASD, alcohol, and pregnancy

To pursue these objectives, we employed qualitative methods of data collection and analysis, drawing on a wide variety of literatures cutting across disciplinary boundaries.

Thesis outline

In Chapter 1, I critically explore the history and current understanding of FASD as a diagnosis. I review the literature on media coverage about FASD, alcohol, and pregnancy, and studies about lived experiences of FASD. This review provides an overview of the current state of the literature to which my thesis contributes. In Chapter 2, I reflect on interdisciplinary research and the different areas of theory informing my work. Specifically, I outline some key components and assumptions of 1) neuroethics and science communication; 2) disability studies;

3) pragmatic bioethics; 4) feminist bioethics; and 5) stigma. I also reflect on the methods and tools we employed: media content analysis and focus group interviews with framework analysis.

Chapters 3 and 4 contain published manuscripts and linking text about our media content analysis. These chapters combine two sets of data from the same study, exploring (in Chapter 3) challenges associated with science and health communication about FASD, alcohol, and pregnancy, as well as (in Chapter 4) the human-interest dimension and possible stereotyped portrayals of people with FASD and women who consume alcohol while pregnant.

Chapters 5-7 contain works and linking text based on our focus group interview study, which builds on the content analysis in Chapters 3 and 4. These manuscripts explore perspectives and experiences of three key FASD stakeholder groups: adults with FASD, their caregivers, and healthcare and allied professionals. The published manuscript in Chapter 5 investigates experiences with and concerns about stereotypes associated with FASD, alcohol, and pregnancy. Chapter 6 (an unpublished manuscript) identifies recommendations to improve public discourse on FASD, alcohol, and pregnancy. Chapter 7 contains a published reflexive chapter exploring and addressing ethical challenges associated with working with adults with neurodevelopmental disabilities. Finally, Chapter 8 (the Discussion and Conclusion) – ties these chapters together and reflects on key findings and take-home messages with the aim of improving the experiences and circumstances of people with FASD and their families in the future.

CHAPTER ONE – BACKGROUND AND RATIONALE

This chapter reviews the relevant empirical literature about FASD, alcohol, and pregnancy motivating my work. Specifically: 1) I explore the history of the FASD diagnosis and current Canadian diagnostic guidelines; 2) I describe studies that have analyzed news coverage about FASD, alcohol, and pregnancy; and 3) I provide a summary of research exploring key stakeholder experiences of and with FASD. A key goal of this review is to provide a critical assessment of the state of the literature in preparation for my doctoral research and thesis.

What is FASD? A brief history

FASD, a complex and heterogenous neurodevelopmental diagnosis of exclusion thought to impact roughly 1%-5% of the population [1-3], results from prenatal alcohol exposure [4]. Although there exist many clinical guidelines informing definitions of FASD worldwide, given the focus of this work in the Canadian context, this project is grounded in two key Canadian diagnostic guidelines published in 2005 and 2016 respectively [4, 5]. FASD can influence many different neurodevelopmental domains, from motor control to executive function to cognition – as I will describe in the section below exploring evolving diagnostic criteria.

The earliest accounts of a potential diagnosis tied to the teratogenic effects of alcohol exposure in utero emerged independently in France in 1968 [6] and in Seattle in 1973 [7-9]. The 1968 paper was not widely taken up, perhaps because it had been published only in French and "was received with skepticism" [10]; however, it has since been recognized for its contribution to the field [11] – notably for its inclusion of 127 cases compared to only 8 in the first American publication [12]. Ultimately, researchers in Seattle proposed and received attention for a novel diagnosis of "fetal alcohol syndrome" (FAS) reflecting a set of identifiable features associated with impairments in the children of "chronic alcoholic mothers" – i.e., a combination of delays, deficits, and differences in growth, development, joints, cardiovascular health, and craniofacial morphology [7] across three categories (not including less common effects) described as follows:

> A) prenatal and/or postnatal growth retardation (weight, length… head circumference…); B) central nervous system involvement (signs of neurologic abnormality, developmental delay, or intellectual impairment); and C) characteristic facial dysmorphology with at least two of these three signs: microcephaly… microphthalmia and/or short palpebral fissures, or poorly developed philtrum, thin upper lip, and flattening of the maxillary area [13].

Some of these early reports proposed ancient texts (e.g., Greek, Talmudic) as possible sources of evidence of FAS throughout history [8], described by Armstrong as the "rhetoric of rediscovery" [14]. Such accounts may have emerged in response to the question "Why hasn't anyone seen this before?" [15] and were criticized: "…the evidence will show that nearly all the statements investing the ancient and medieval past with precognition of this disorder are wrong" [10], mostly by pointing to a lack of historical and sociological context for such statements and to poor citational practices [14]. Consequently, likely the earliest empirical evidence of alcohol's teratogenic effects on a fetus emerged in the 18th or 19th centuries [10, 15, 16]. However, it was not until the 1973 publications that the possibility of a diagnosable syndrome emerged.

The diagnosis soon expanded to incorporate subtler cases that were missing some of the visibly identifiable features of FAS. In 1978, Clarren and Smith labelled such cases "suspected fetal alcohol effects" (FAE) – not intended as an official diagnosis (though it was soon taken up as such), but as an at-risk designation [17] – as clinicians recognized a spectrum of outcomes:

> At the most severe end of the spectrum are patients with the unique constellation of anomalies initially termed 'fetal alcohol syndrome.' Along the rest of the

> continuum toward normal are persons with every subcombination of fetal-alcohol-syndrome anomalies. Each anomaly can independently vary in severity and grade into the normal range [18].

However, as several reviews of the history of FASD have pointed out [16, 19], the term FAE became confused and was often misapplied, which led to it falling out of favour [17]. Over the next two decades, further research would help to refine understandings of the possible effects of alcohol on a fetus, including into social, behavioural, and emotional domains – although this “diagnosis expansion” into increasingly uncommon domains was critiqued for expanding who might be at risk or who should be diagnosed, leading to public alarm and moral panic [14].

In 1996, the American Institutes of Medicine (IOM) proposed guidelines for five related diagnostic categories [20], not yet collected under the umbrella of ‘FASD’. However, some criticized the guidelines as “vague… resulting in an inconsistent approach across clinics” [19] – something that later guidelines would explicitly address (e.g., [21]). For the IOM, the first two categories (i.e., FAS with or without confirmed maternal alcohol exposure) matched existing criteria: “evidence of a characteristic pattern of facial anomalies… of growth [issues, and]… of [central nervous system] neurodevelopmental abnormalities” [20]. A third category, partial FAS (pFAS) with a history of maternal alcohol exposure, reflected cases where not all features could be confirmed; however, the report took pains to explain they did not mean to suggest that “‘[p]artial’ denotes… that the condition might not be as severe”. They applied this category to, for example, adults who no longer presented with classic childhood features. This category also introduced broad and imprecise behavioural and cognitive symptoms. The last two categories reflected a group of patients with symptoms uncertainly attributed to alcohol: alcohol-related neurodevelopmental disability (ARND), referring to “neurodevelopmental problems” and alcohol-related birth defects (ARBD), referring to “physical anomalies” [20].

Also in 1996, Streissguth et al. published a report about the “secondary disabilities” of FASD (e.g., mental health issues, trouble with the law, substance use, unemployment), which contrast with more biologically-grounded impairments that are sometimes called “primary disabilities” (i.e., the actual “CNS dysfunctions inherent in the FAS… diagnosis”) [22]. As defined, “secondary disabilities” (more often referred to now as “secondary conditions”) relate to problems that people appear not to be “born with” – as in, problems that arise as people with FASD integrate into society as they age. The report also identified protective factors (e.g., a stable and nurturing home, early diagnosis). This attention to an array of more social concerns was certainly welcome, since, as discussed, some scholars were also calling for a greater focus on the social conditions attached to diagnoses of FASD. As Armstrong argued in 1998:

> …[seeing] alcohol as the sole cause of the observed outcome blinded doctors to the social context in which prenatal exposure to alcohol occurred and to any potential ameliorating or exacerbating factors. Every woman was equally at risk; yet, that assumption contradicted research findings that suggested that even among chronic alcoholics, not every woman would have a baby with FAS [14].

Around that same time, Astley and Clarren published guidelines introducing the “4-Digit Diagnostic Code” [23]. Essentially, the authors aimed to create a more rigorous and quantifiable means of measuring the impact of alcohol across the four typically measured dimensions of the diagnosis: 1) growth; 2) facial features; 3) CNS impairments; and 4) prenatal alcohol exposure. One important reason for creating four separate scales was “not to imply that an individual's disabilities and/or anomalies are confirmed to be caused by their prenatal alcohol exposure” [23]

– a concern that had also been raised by critics of the social construction of FAS [14, 24, 25]. Since the publication of the IOM guidelines and the 4-Digit Diagnostic Code, several guidelines and studies have attempted to analyze, compare, or reconcile these approaches (e.g., [26, 27]).

In Canada, Chudley et al.'s 2005 diagnostic guidelines "harmonized" the approaches by recommending the use of the 4-Digit Diagnostic Code for assessment and the IOM terminology for diagnosis under the umbrella of FASD (i.e., FAS with/without confirmed alcohol exposure, pFAS, and ARND – but not ARBD) [4]. Importantly, the earliest use of the term 'fetal alcohol spectrum disorder(s)' in a scientific publication appears to have been in 2000 by Streissguth and O'Malley [28]; most histories of FASD fail to discuss the precise origin and evolution of the term FASD itself, other than to point to its adoption in the early 2000s (e.g., [29]). Ultimately, these guidelines recommended that diagnosis of FASD occur only after other possibilities have been excluded – at which point a complex multidisciplinary approach should be adopted.

Today, Canadian guidelines have fully embraced FASD itself as a diagnosis [5], not only as a mere umbrella term [4]. The 2016 guidelines harmonized additional diagnostic approaches and terminology (including the DSM-5 approach) and updated the 2005 guidelines based on a survey of experts and emerging evidence. These new guidelines included only three categories:

1) FASD with sentinel facial features;
2) FASD without sentinel facial features; and
3) an at-risk designation (not diagnosis) to ensure appropriate monitoring and care as needed (i.e., "At Risk for Neurodevelopmental Disorder and FASD, Associated with Prenatal Alcohol Exposure").

As in past guidelines, the same set of sentinel facial features were included; however, growth is no longer considered a key criterion. Additionally, patients must present with deficits in three of ten “central nervous system,” “neurodevelopmental,” or “brain domains”: “motor skills, neuroanatomy/ neurophysiology, cognition, language, academic achievement, memory, attention, executive function including impulse control and hyperactivity, affect regulation, and adaptive behaviour, social skills, or social communication” [5]. In removing the sub-diagnoses, which were often incorrectly understood as part of a linear progression from severe (e.g., FAS) to mild (e.g., ARND), these most recent guidelines communicate the complexity of FASD.

Importantly, as the medical literature and an understanding of the teratological effects of alcohol on pregnancy has evolved, so has public understanding, discourse, and health messaging. As Armstrong argued in her seminal 1998 analysis of the evolution of FAS, when the medical diagnosis emerged, the conservative social and political climate in the US at the time contributed to public alarm and moral panic about alcohol and pregnancy [14]. Armstrong tied this panic to social expectations about the behaviour of women in general and pregnant women in particular – pointing directly to medical literature that framed such women as having “clearly failed to fulfill their roles as nurturers” [14]. Armstrong ultimately concluded that “moral fervor powered the discovery of [FAS] as much as medical curiosity” [14]. With such concerns in mind, I turn to a series of studies that explore the framing of FASD, alcohol, and pregnancy in public discourse.

FASD, alcohol, and pregnancy in the media

Media, key sources of public information about health and science, are thought to both reflect and affect culture [30]. In the case of diagnoses linked to limited public knowledge and awareness such as FASD [31-33], media may act as key sources of information that could potentially generate and perpetuate common disability narratives and stereotypes [34, 35]. To the best of my knowledge, prior to our FASD media content analysis, no study had provided an in-depth account of depictions of FASD, alcohol, and pregnancy in Canadian news. However, a paper from 2013 raised concerns about Canadian news linking FASD with gang violence and Indigenous peoples [36], and an unpublished 2016 study that was part of the "Looking After Each Other: Dignity Promotion Project" analyzed online news, largely in rural Manitoba [37]. In addition, five other analyses have been published in three principally English-speaking countries: the US [38, 39], the UK [40], and Australia [41, 42]. Each paper had a slightly different focus (e.g., alcohol and pregnancy over FASD itself), methodology (e.g., framing analysis versus content analysis), and medium (e.g., print versus television news). What follows is a review of each of these papers, including summaries and comparisons of their findings.

The first article on this topic is Janet Golden's 2000 paper titled "'A tempest in a cocktail glass': Mothers, alcohol, and television, 1977-1996" [38] – later updated and republished as part of her 2005 book *Message in a bottle: The making of fetal alcohol syndrome* [15]. Her goal was to "[trace] the changing portrayal of alcohol and pregnancy" across thirty-six evening newscasts (1977-1996) from the three major American TV news networks (ABC, NBC, and CBS). Golden argued that alcohol had been portrayed positively in entertainment and advertising media (in contrast to more critical news media) and was "rarely compared with the use of other drugs" [38]. Ultimately, Golden identified a shift in news coverage about alcohol and pregnancy from a public health frame about white, middle-class women (1977-1986) – which sometimes aimed to elicit sympathy for a "repentant" mother and her child [15] – to a public danger frame focused on deviant, substance-using minority women (1987-1996)[1]. Golden also identified a key social issue connected to this shift: emerging "moral panic" over the use of "crack cocaine" [38], where "[s]ympathy for women caught up in a cycle of poverty and addiction began evaporating as images of damaged 'crack babies' filled the airwaves and Americans began to view them as a

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[1] Although this latter frame included Latina and African-American women, an emerging thread that will be seen in later studies, including our own, focused on the connection between FAS/FAE and Indigenous communities.

social burden, draining resources, filling jails, and threatening the social order" [15]. Golden concluded that, although there were few news stories about alcohol and pregnancy overall, these narratives were shaped by stories about drugs like crack cocaine – which shifted the burden and blame of substance use and FAS itself onto 'deviant' birth mothers. Questions about 'fetal rights' also began to emerge regarding policy questions of whether to assist or punish such mothers.

In 2008, Connolly-Ahern and Broadway published a framing analysis of 236 articles from thirty-four print news sources in the Northeastern US (1997-2007) titled "'To booze or not to booze?' Newspaper coverage of fetal alcohol spectrum disorders" [39]. They identified three main frames: 1) *dangerous mothers* (i.e., dangers to their future children, themselves, and to society; n=50); 2) *fetal wellness* (i.e., drinking advice for pregnant women, predominantly suggesting abstinence, but sometimes that small amounts of alcohol may be safe; n=50); and 3) *victimization* (i.e., people with FASD as victims of birth mothers, victimizing others, or societal burdens; n=136). They concluded that, without training, "the complexity of health-oriented issues may overwhelm the media, resulting in a chaotic discourse that ill serves audiences" [39].

In 2010, Lowe et al. published an analysis of 401 articles in UK print news (1985-2008) titled "Under the influence? The construction of foetal alcohol syndrome in UK newspapers" [40]. They found that Connolly-Ahern and Broadway's frames did not "adequately represent the dominant frames" in their UK-based analysis [40]. Instead, they identified three broader frames: 1) *alcohol as a problem for society* (i.e., seen as an "extreme reaction" outside of the UK related to a "neo-prohibition movement", shifting to more overt concern about a rise in women's alcohol use and FASD); 2) *drinking advice or warnings* (i.e., uncritically repeating press releases or the views of lobby groups on novel guidance or research findings, with coverage of policy reflecting some debate about the uncertainty of health advice and the state 'over-stepping' by telling people what to do); and 3) *policing pregnancy* (i.e., concerns that guidance and advice unnecessarily restricts women's lives, often from the perspective that women already know not to harm their fetuses and therefore such advice is "unwarranted"). Some articles mention FASD as a possible "outcome of colonialism" – a problem for other countries and peoples.[2] They concluded that FASD coverage reflected growing concerns over alcohol consumption broadly, with alcohol in pregnancy now perceived "as a threat to 'moral order' through irresponsible parenting". As in, news about FASD, alcohol, and pregnancy raised questions about what makes a "good mother", suggesting that a "moralizing framework" had overtaken FASD discourse in the UK [40].

In 2013, Henry published an article titled "Moving Beyond The Simple: Addressing The Misuse of the FASD-Gang Link in Public Discourse" focused on a single dimension of FASD news coverage: connecting FASD with gang violence and Indigenous communities [36]. He critiques this connection strongly, arguing that such narratives are rooted in a biomedicalization of challenges faced by Indigenous peoples – which serve to blame Indigenous communities "for their own actions of alcohol addictions" while ignoring many other social determinants of health [36]. Henry uses one article published in the National Post in 2010 to launch his discussion. Even though most of the other studies reviewed here identified some news coverage connecting FASD with Indigenous peoples, this was the only article to center concerns about such coverage.

In 2016, Eguiagary et al. published a framing analysis of eighty news articles published in twenty-one Australian newspapers in 2012 titled "Sympathy, shame, and few solutions: News media portrayals of fetal alcohol spectrum disorders" [41]. They noted two dominant frames: 1) *discourses of victimhood* as sympathy-promoting (i.e., for people with FASD, mothers); and 2)

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[2] Lowe et al. identified a book titled *The Broken Cord* by Michael Dorris [43] as being one key source of media narratives connecting FASD with Indigenous communities. In this book, which serves as his memoir, Dorris tells the story of the challenges he faced raising his adoptive son – a Lakota child who was eventually diagnosed with FAS.

discourses of blame and wrongdoing as shame-promoting (i.e., for mothers, professionals, and governments and government institutions) [41]. In the former, children with FASD were often framed as hopeless victims of their birth mothers. Relatedly, in the latter frame, with some actors positioned as victims, others served as blameworthy villains (e.g., mothers, governments). They argued that these contradictory messages confusingly "hold different parties responsible for the impact of FASD" [41], leading them to call for more supportive messaging for women who drink while pregnant rather than promoting further stigmatization. They pointed to the importance of understanding contextual factors and actors involved in drinking, pregnancy, and risk of FASD – including several not discussed in the news: 1) the alcohol industry and related advertising; and 2) the role of supportive (or unsupportive) partners, families, and communities [41].

Also in 2016, Healthy Child Manitoba conducted (but did not publish) a media content analysis of eighteen online news sources (2008-2016) across eight communities in Manitoba titled "Framing FASD: A qualitative content analysis of rural Manitoba media coverage" [37].[3] Their major findings were that stories typically focused on "individual-level circumstances", rather than on broader social factors and "system-level issues" [37].

In 2017, McCallum and Holland published a framing analysis of 110 "media items" from Australian print, online, and TV news and parenting websites (2013-2014): "'To drink or not to drink': Media framing of evidence and debate about alcohol consumption in pregnancy" [42]. This publication appears to have grown out of a report they previously published in 2015 for the Foundation for Alcohol Research and Education (FARE) titled *Conversations about alcohol and pregnancy* [44]. Attending to debate about abstinence-based health policies, they identified two dominant frames: 1) c*ontested evidence and advice* (i.e., low-to-moderate drinking framed as

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[3] Their sample overlapped a bit with our media study (i.e., we both included the Winnipeg Free Press during the period of 2008-2015), but their overall findings differed a bit given their focus on local rather than national news.

harming or not harming a fetus); and 2) *women's rights* (i.e., that drinking in pregnancy is a woman's decision, and that she ought not be judged for related behaviour). They also identified three less prominent frames: 3) *FASD crisis*; 4) *blame risk-taking mothers*; and 5) *community responsibility*. As in previous studies, they found coverage that connected FASD and Indigenous communities, discussed only briefly: "[A]part from a subset of stories about FASD in Indigenous communities, FASD was not a dominant lens through which the majority of stories were reported".[4] Additionally, they argued that FASD itself was not often the focus of news coverage, merely a "backdrop for discussion about alcohol and pregnancy" [42]. They concluded that their sample questioned "unequivocal" advice about abstinence in pregnancy. However, they argued that news should not be seen as working against health experts or messages but embraced for "its potential to invite audiences as citizen-consumers to appreciate the complexities, contradictions and uncertainties of scientific evidence, public health advice and lived experiences" [42].

In comparing the findings of these studies, several trends that also appear in our media analysis (Chapters 3 and 4) emerge. First, discourse about FASD contains racialized and colonial elements: Golden points to panic about "crack babies" and deviant women of colour [15], Lowe et al. discuss coverage of FASD and colonialism [40], the FARE report has a section on FASD in Indigenous communities [44], and it forms the basis of Henry's news analysis of gang violence and FASD [36]. This narrows over time to focus most prominently on Indigenous groups: Native Americans in the US, Aboriginal people and Torres Strait Islanders in Australia, and First Nations, Métis, and Inuit in Canada. Second, alcohol consumption in pregnancy raises questions about culpability and blame (e.g., Connolly-Ahern and Broadway identify a *dangerous mothers*

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[4] These concerns are discussed in much more detail in their original 2015 report. Importantly, they point to another thread that will emerge in Chapter 5, about how coverage of FASD and Indigenous communities could serve "to distance non-Indigenous women from the risks associated with drinking alcohol during pregnancy" [44].

frame including concerns about "fetal abuse" [39], Lowe et al. ask questions about what makes a "good mother" [40], Eguiagary et al. point to the perhaps contradictory frames of sympathy and shame which suggest different answers about who we ought support or condemn [41]). Third, the media report or reflect on health advice for pregnant women – and the analyses reveal concerns about how to effectively report scientific uncertainty. Finally, the portrayal of people with FASD moves between categories of innocent victim and deviant victimizer, hopeless and inevitable in either case [45]. Such concerns are also reflected in our focus group data (Chapters 5 and 6).

The studies described here form a body of scholarship that my thesis builds upon in the Canadian context. In 2018 and 2019, we published two papers reflecting different slices of the dataset (Chapters 3 and 4 respectively): "Stigmatisation, exaggeration, and contradiction: An analysis of scientific and clinical content in Canadian print media discourse about fetal alcohol spectrum disorder" [46] and "Stereotyping and stigmatising disability: A content analysis of Canadian print news media about fetal alcohol spectrum disorder" [47]. While we found similar coverage and themes to other studies, we focused on different questions and dimensions, such as disability tropes and stereotypes in news (i.e., people with disability as victims, as villains), as well as ethical considerations around science and health communication about alcohol, pregnancy, and FASD – paying particular attention to FASD, alcohol, and pregnancy in the context of colonialism. I elaborate on both points in the methodology section, connecting our publications to scholarship and theory from disability studies and neuroethics, respectively.

In short, in pragmatic health ethics, as well as in feminist bioethics and disability studies, understanding the lived experiences of people affected by a given condition is necessary to improve their situations and to understand the complex moral dilemmas and choices associated with those situations [48]. While news coverage of FASD, alcohol, and pregnancy can indirectly provide information about lived experiences, it mostly speaks to public framing of FASD or alcohol consumption during pregnancy. As discussed, that coverage can potentially promote stereotyped and stigmatizing constructions of neurodevelopmental disabilities like FASD [49]. This project aims to understand the experience of FASD with respect to stigma [50] and, therefore, attends to the perspectives of those affected by FASD regarding news coverage.

Experiences of key stakeholders associated with FASD

To understand the perspectives of those affected by FASD, a helpful place to start is with a 2018 metanalysis of qualitative studies that included the perspectives of people with FASD or their families [51]. Notably, only two of the eighteen studies included in their analysis focused on the lives and views of people with the diagnosis itself [52, 53]. Given the study's inclusion and exclusion criteria, and time since its publication, I have identified additional publications about people with FASD. Still, the concern remains that many qualitative studies aiming to include the views of these often-excluded stakeholders focus primarily on the family over the individual. In this section, I describe the findings of the publications that have included the voices of people with FASD [52-62], two first-person perspective chapters in academic texts by adults with FASD [63, 64], and several academic theses [65-68]. The findings highlighted some common experiences for people with FASD: difficult circumstances and daily challenges [52], feeling different or socially isolated [53], and, crucially, a lack of support [54] especially in transition out of school or child welfare into adult life and systems [60]. People with FASD did sometimes report positive experiences of feeling cared for by parents (often adoptive), who serve as their principal advocates [57].

Given the need for a greater accounting of the experiences of people with FASD over other stakeholders, this section will focus primarily on describing the above studies. In terms of caregiver experiences, parents also experience a range of overlapping difficulties in their roles as biological, adoptive, foster, or kinship caregivers for people with FASD. Parents manage care for a child with impairments – and grief associated with a diagnosis – while biological mothers additionally contend with guilt and judgement from others [69, 70]. However, such diagnoses can also help parents feel relief that they have an explanation for their child's behaviours. Parents may also feel unsupported (especially by professionals), perhaps having to take up the role of advocate [57, 71-74]. While often proud of their child's accomplishments, parents in almost every study expressed concern for their child's future [69, 70, 72-77]. Finally, studies exploring the perspectives of healthcare and allied professionals mostly addressed professional knowledge, training, attitudes, and providing health advice about the impact of alcohol in pregnancy [78-80].

People with FASD

In 2006, Ryan and Ferguson published two papers based on the same study exploring the experiences of people with FASD and other key stakeholders (e.g., parents, diagnostic team, teachers): 1) "The person behind the face of fetal alcohol spectrum disorder: Student experiences and family and professionals' perspectives on FASD" [54]; and 2) "On, yet under, the radar: Students with fetal alcohol spectrum disorder" [55]. To tell the stories of five children with FASD in Alaska (which was the state with the highest FASD prevalence), they conducted 135 in-depth interviews with 71 participants; although children with FASD were included, parental and professional voices predominated. The researchers also conducted 400 hours of participant observations both at home and in school settings, and incorporated key documents and texts such as policy, individualized education programs (IEPs), and news. Although the voices of the children were included, most of the reported data appeared to come from other stakeholders.

In the first paper, they focused on the stories of people with FASD ("the person behind the face") across three themes: 1) *fleeting success and competence* (i.e., that people with FASD demonstrate some success in school and competence outdoors, but still require lifelong support); 2) *vulnerable students and families* (i.e., that they have lived difficult circumstances and lack support in transitioning out of the school system); and 3) *anticipated trajectories* (i.e., that children with FASD are seen as "doomed" to an "inevitable" future of "petty crimes, drug and alcohol use… and prison") [54]. The authors also briefly discussed possible social and cultural stigma tied to FASD and the "Alaskan Native community". They call for further supports that foster competence, stability, and belonging for people with FASD, especially since "receiving a diagnosis did not automatically lead to increased or better services".

In the second paper, they focused on the broader social context of diagnostic services and education [55]. They found three themes: 1) *"On, yet under the radar"* (i.e., that, while FASD awareness and government action had increased, placing FASD on the public's radar, children with FASD still fell "through the cracks"); 2) *"I don't do anything differently with Oscar"* (i.e., that both experienced and inexperienced teachers treated children the same – the former giving every student individualized support, the latter not knowing how to adapt to individual needs); and 3) *"If I had known then what I know now…"* (i.e., that adoptive families felt overwhelmed by their child's behaviours and that they lacked access to supports and services, which had a serious impact on their lives and relationships). The authors concluded with a call for better coordination of and an increase in services provided to children with FASD and their families.

These same ideas and themes emerged, independently, in our interview study (See Chapters 5 and 6) – i.e., the importance of lifelong support, difficult circumstances, anticipated hopeless futures, and the challenges professionals and caregivers face when supporting people with FASD. Of course, given our study's focus on communication and improving discourse, these experiences are described often in service of improving discourse about FASD.

Between 2005-2007, Duquette et al. published several papers based on the same study describing the perspectives of Canadian and American adolescents with FASD (aged 15-20) about their experiences in school [56-59]. A key finding was that adolescents with FASD who persisted in high school largely did so because of their adoptive parents' academic and emotional support and, centrally, strong parental advocacy. As in the studies by Ryan & Ferguson, the perspectives of other stakeholders were also included (i.e., the adoptive parents) to build a more holistic picture of the reported experiences, with parental accounts sometimes serving to fact-check their children's[5]. Similarly, these papers provided accounts of a small number of cases (eight), painting rich pictures of the experiences of specific individuals. Overall, the focus of these papers was primarily school integration, with calls for greater understanding and support.

Over the last two decades Fuchs and Burnside have published studies about FASD in the child welfare system, some of which have focused on the experiences of youth transitioning out of that system into adulthood and presumed independence [60, 62]. They conclude that people with FASD need particularly stable placements and greater support for caregivers, as well as a restructuring of a system that favours release from care at prescribed ages (the notion of being "bound by the clock") rather than in a way that makes sense for a particular individual [60].

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[5] In our work, we include multiple stakeholder groups, but not with the aim of fact-checking; we argue that people with disabilities are not always taken as seriously as their caregivers, or that the two groups may be unhelpfully merged into a single set of 'stakeholders' – even when they have distinct or contrasting views or needs. Such needs are explored in literature about autism, which separates 'autistic stakeholders' from 'autism stakeholders.' As Orsini explains: "I use the term 'autism movement' to distinguish activists or advocates more interested in pressing for policy change around the treatment for autism and concern with its causes, versus the term 'autistic movement,' which normally refers to the efforts of activists to create a positive identity for autistic people using… a disability rights frame" [81]. While the situations and contexts of autistic people and people with FASD are different, the importance of paying attention to the views of people with a diagnosis themselves is the same.

In 2011, two first-person chapters were published as part of a book titled *Fetal alcohol spectrum disorder: Management and policy perspectives of FASD* [82]. In the first, Myles Himmelreich, a well-known advocate and public speaker, recounts his life story [63]. Given such negative discourse about FASD, he chooses to "share not only the loss and hardships but also all the triumphs and successes". He outlines challenges he faces, but he also describes his strengths (e.g., sports, public speaking). His chapter ends hopefully: "Today, I know I'm not just another statistic living with a disability – I'm Myles Himmelreich, a successful young man who has found his ability" [63]. Since 2011, Myles has co-led a survey exploring the health and physical dimensions of FASD [83, 84], and he mentors youth with FASD as a consultant for the Asante Center [85]. In the second chapter, Charlene Organ tells us about her life with FASD – also discussing challenges and positive experiences [64]. She emphasizes the importance of "asking for help when you need it", and, as in the findings of Duquette et al. [57], how her supportive relationship with her adoptive mother enables her successes. Charlene's story explains the importance of support – from teachers, family, friends, and beyond. Charlene ends her chapter hopefully as well, saying that her mother "wants the rest of the world to know that I am special and will show the world that, with love and understanding, anything can be accomplished" [64].

Also in 2011, Stade et al. conducted a study using unstructured interviews with the goal of describing children's experiences of FASD [53]. They included twenty-two children aged 6-18 living in both urban and rural settings in Canada diagnosed with FAS, pFAS, or ARND. Their core finding was that "living day-to-day with FASD meant feeling different". They identified three themes: 1) *knowing the disability* (i.e., understanding their limitations or why they behave as they do, and feeling the unfairness of such a disability – especially as related to birth mothers drinking); 2) *feeling alone-feeling supported* (i.e., feeling socially isolated without friends, but receiving love and support from parents)*;* and 3) *overcoming the disability*. They conclude with a call for more support and funds, for socialization programs, programs to help foster strengths, and destigmatizing children with FASD to help strengthen their self-esteem.

In 2012, Salmon and Buetow conducted a study using two qualitative methodologies to understand day-to-day challenges faced by people with FASD – a description of experiences with transcendental phenomenology and grounded theory "to understand the meanings grounded in…[those] experiences". They also anchored their use of distinct approaches in philosophical pragmatism [52], as I do in my work. They conducted unstructured interviews with fourteen New Zealanders aged 14-37 with FAS or FAE and identified six themes employing the first methodology: 1) *daily challenges in the classroom*; 2) *daily challenges in the workplace*; 3) *coping with mental health issues*; 4) *memory problems*; 5) *socialization difficulties*; and 6) *involvement with the law and authority*. Using the second methodology, their emerging theory suggested participants felt unsupported by social and health systems, later experiencing serious "secondary disabilities" (i.e., criminal behaviour, employment challenges, and social problems).

Finally, over the past two decades, several theses have explored the experiences of people with FASD [65-68]. Erb interviewed four participants who learned their diagnosis as adults with implications for social work practice [65], Massey interviewed five women with FAS with implications for the practice of psychology [66] Copeland interviewed young adults with FAS to learn about friendships [67], and Abraham explored needs of parents with FASD [68].

Over the past few decades, while qualitative research centring the voices of FASD stakeholders has grown globally, it remains critically under-studied. Even when these voices are included in research, studies often conflate or combine their views with those of their caregivers. In Canada, a world leader in FASD research [86], there have only been a few experiential studies

– a neglected area of research that my thesis aims to address. Importantly, even where such studies exist, they are not always taken up in other literatures that could benefit from these perspectives (e.g., health sciences, biology and physiology, prevalence research). As my thesis exists at the intersection of numerous disciplines, I aim to bridge some of these gaps and provide helpful experiential data to policymakers, healthcare professionals, and people with FASD.

Synthesis

As described in this literature review, the history of FASD is complex, controversial, and fraught with uncertainty. While diagnostic criteria have been both clarified over time and expanded, some critics of the diagnosis and its history have pointed to its connection to judgemental attitudes, racialized and racist assumptions, and an unhelpful moral panic over the behaviour of certain groups of women. The existing literature exploring FASD, alcohol, and pregnancy in the media have focused primarily on alcohol and pregnancy and less on FASD – which our work aims to balance. Similarly, much of the existing qualitative interview research focuses on families and professionals, while this study aims to bring all voices into conversation, ultimately centring the views, experiences, and recommendations of people with FASD.

Unlike so many other diagnoses, FASD directly points to a singular cause – prenatal alcohol exposure, framed as the individual, shame-able, and blame-able actions of dangerous deviant racialized women. In this socially flammable context, it should be no surprise that questions of stigma and discrimination have been raised [49, 87, 88]. Throughout this thesis, I address these questions and concerns through a media analysis and connected focus group study, learning what gets said about FASD, alcohol, and pregnancy, and what stakeholders impacted by this discourse think and recommend. In Chapter 2, I explore stigma in more depth, and elaborate on its connection to FASD across several manuscript chapters (4 and 5 in particular).

CHAPTER TWO – METHODOLOGY, THEORETICAL ORIENTATIONS, AND CORE CONCEPTS

Interdisciplinary research

My thesis exists at the intersection of several related fields and disciplines. Consequently, it does not have a singular driving ontology or methodology rooted in one disciplinary tradition. Instead, I have taken up theoretical assumptions, core concepts, and methods from different areas of scholarship to conduct interdisciplinary research in health ethics [89, 90]. In this chapter, I outline key theoretical orientations shaping this project and its methods including: 1) neuroethics & science communication; 2) empirical bioethics & pragmatism; 3) disability studies; 4) feminist bioethics; and 5) the concept of 'stigma'. In addition, I describe the two principal research methods I employed throughout my thesis: media content analysis and focus group interviews[6].

Neuroethics and science communication: Neuroscience in the news

When I was still an undergraduate student in neuroscience, I became increasingly aware of and frustrated by uncritical coverage of neuroscience findings. I worried about scientific hype, overpromising, and loss of public trust should those promises be broken. I believed neuroscience could meaningfully affect how we understand ourselves and our institutions, but worried that some resulting public knowledge or action would be based on uncritical or hyperbolic coverage.[7] Around that time, I took a course in neuroethics where this concern was reflected back at me via the work of Dr. Eric Racine – who eventually became my PhD supervisor [92]. Perhaps naively, I believed that the solution to bad neuroscience news coverage was to produce more accurate coverage. This idea informed my early work – I wanted to understand how people with neuro-diagnoses were portrayed in Canadian news, to provide suggestions on how to improve the

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[6] See Chapter 7 for reflection on the logistical and ethical challenges of research interviews with adults with FASD.

[7] For an example of the kind of concerning coverage that motivated me, please see *Media, politics and science policy: MS and evidence from the CCSVI Trenches* [91] for discussion about Liberation Therapy – a now disproven theory and proposed treatment associated with multiple sclerosis that was widely covered by Canadian news, and that became a seriously debated issue as patients sought funding for and approval to access this option.

scientific accuracy of health and science communication. As I began this work, I came to understand some complexities of communication, public understanding, and how the production of science relates to social values, actors, and cultural practices too. What follows are the many literatures in which this understanding became grounded, as my project evolved over time.

Science communication

Media is thought to both reflect and affect culture [30]. From this core assumption – common in the field of cultural studies – springs much of the rest of this doctoral project. At its core, my thesis engages with this idea as a central challenge: that news describing complex and ill-understood health topics (e.g., FASD [31-33]), as well as representations of marginalized groups (e.g., Indigenous peoples), shape and are shaped by potentially problematic or incomplete public, scientific, and institutional knowledge.[8] Research suggests that public engagement with science news is a complex process incorporating many factors beyond accuracy – such as prior knowledge, ideology, and biases [94]. Consequently, attending only to the factual accuracy of science reporting may not resolve all issues of knowledge translation and public understanding; however, describing what and how media report on FASD, alcohol, and pregnancy can still help us understand the landscape of information available to Canadians, which could inform Canadian constructions of FASD, as well as the social values structuring and informed by that information.

Additionally, research suggests that stakeholders sometimes present science and health information in overly optimistic or exaggerated ways (e.g., [91]). By stakeholders, I do not only mean actors generating news (e.g., journalists, editors), but other interested parties like industry,

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[8] Media that reflect and impact public understanding are not limited to news; portrayals in film and television, or in advertising, also matter (e.g., see this academic blog post I co-authored on *Speechless*, a show about a teen with cerebral palsy [93]). However, I shift here from media broadly to news alone, since news has traditionally been associated with attempts to disseminate information responsibly; whether it does so is another matter. In theory, obligations of news toward information make it a useful object of study and target of messages for improvement.

advocacy organizations, scientists, and universities [95-97].[9] Ultimately, a media product that overemphasizes benefits, exaggerates current scientific capabilities, or fails to discuss risks and limitations can lead non-experts to unrealistic understandings of what medicine and science can do.[10] If members of the public then act on those exaggerations, either individually (e.g., negative attitudes toward and discrimination against people with FASD) or collectively (e.g., through norms and formal legislation), it risks causing harm to vulnerable communities and individuals. These concerns, especially in the context of communication about neuroscience (which has been controversially described as a particularly persuasive form of scientific evidence [98-100]), have been at the forefront of discourse in neuroethics, as I describe below.

Neuroethics and the study of neuroscience communication

Neuroethics, a relatively new area of scholarship, often traces its roots to several key conferences near the turn of the millennium [101]. It is generally understood to have emerged in response to rapid advances in neuroscience in the late 1990s and early 2000s, to address ethical issues associated with novel neurotechnologies (e.g., brain-computer interfaces to help patients with locked-in syndrome communicate [102]), neurointerventions (e.g., deep brain stimulation to reduce tremors in Parkinson's Disease [103]), and the implications of neuroscience findings for public institutions (e.g., brain-based evidence used in courts of law to inform understandings of culpability [104]). There are many definitions of the field (with disputes about if it is even a field at all)[11], but early definitions pointed to a dual focus blurring lines between empirical and

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[9] This includes universities exaggerating findings in institutional press releases [96], or scientists over-emphasizing the novelty or uniqueness of their findings in abstracts – perhaps to publish in high impact journals [97].

[10] This uncritically optimistic mode of science communication has been described colloquially as 'hype and hope' [95]; however, uncritically pessimistic science communication can also occur (i.e., 'doom and gloom') – which is likely the more relevant kind of hyperbole when communicating information about FASD, alcohol, and pregnancy.

[11] Please see *Debates about Neuroethics: Perspectives on its Development, Focus, and Future* [105], a volume I co-edited, which explores questions on the value, scope, and evolution of neuroethics as an object of academic study.

normative approaches: the ethics of neuroscience and the neuroscience of ethics [101] – as in, the study of ethical challenges associated with advances in neuroscience and medicine, as well as the possible influences of neuroscience on ethics theories and approaches (discussed more below).

From its inception, neuroethics researchers have also studied neuroscience in public discourse, exploring concerns associated with neuroscientific hype for novel neurotechnologies (e.g., uncritical coverage of functional magnetic resonance imaging [106-108] or transcranial direct current stimulation [109]), public engagement with complex and controversial social issues (i.e., disorders of consciousness [110], persistent vegetative state [111], brain death [112], and the Terri Schiavo case [113]), and critiques of the power and philosophical implications of 'brain-based explanations' (e.g., media portrayals of neuroscience studies of free will claiming to undermine its existence [114]). These studies have provided a critical lens through which to view public portrayals of both the capabilities and limitations of neuroscience knowledge. It is with this contribution in mind that we engaged in research about Canadian news coverage about the portrayal of a neurodevelopmental disability (i.e., FASD) – a diagnosis that may mean a person has fundamentally distinct brain architecture from typically-developing individuals.

Even in the earliest of these studies, scholars called for multidirectional communication, relationship-building, and engagement across key stakeholder groups (e.g., neuroscientists, social scientists, the public, media) [106]. This mode of engagement roots science communication in pragmatic approaches to deliberative discourse, ensuring not only that knowledge translation can lead to better-informed publics, but that (neuro)scientists remain aware of issues of concern to those publics – as well as social values and implicit assumptions that may animate their work.

Pragmatism and bioethics: Connecting normative conclusions to empirical data

As discussed, neuroethics, as an area of inquiry, is intimately connected to debates about the connection between empirical data and normative conclusions. The "neuroscience of ethics" is often grounded in an assumption that neuroscience can or should impose its knowledge on or supersede existing ethics theory – i.e., that understanding the neurobiological mechanisms of moral reasoning ought to revolutionize and impact ethics theories and approaches [115]. In response, a number of common critiques of neuroethics have emerged [116]; specifically, that 1) neuroscience should not be seen as the sole source of evidence to influence our moral theories – i.e., that we must avoid neuroscientism and embrace interdisciplinary sources of knowledge – and 2) neuroethics must not focus so narrowly on emerging neurotechnologies as a marker of its distinctiveness and that scholars in this area should encourage exploration of broader and more interconnected questions in bioethics and medicine. Racine and Sample [116] argue that one way to move in this direction is to undergird neuroethics work with a "pragmatist reconstruction" of what may currently be conceived of as neuroethics. What follows are several core assumptions of pragmatic approaches to ethics and scholarship that my work embraces and acts upon.

Pragmatist assumptions

As described by Racine, "pragmatic naturalism does not linger on the question of whether ethics is an entirely empirical discipline… or a unique normative discipline… the debate centers on how empirical knowledge can be brought to bear meaningfully in the pursuit of moral good(s)…" [117]. Racine also articulates several key assumptions, building on the ideas of philosophical pragmatist John Dewey, which animate my research. These include the idea that ethics ought to be "deliberative, adaptive, creative," engaging in democratic exchanges to build consensus around a plurality of possible acceptable moral outcomes (an idea we operationalize through focus group interviews); that ethics must be *situationalist*, where attending to context enables us to understand and then act on both everyday and dramatic ethics challenges [118] in a given situation; that ethics can be interdisciplinary, empirical, and experiential; that "social networks and systems help shape, enhance, and constrain our ability to make and act on moral decisions"; and that a pragmatist ethics is action or practice-oriented, where "moral deliberation should also lead us to act and behave ethically" [117]. Different methodologies, concepts, or principles may be instrumentally useful when both seeking to understand a given *situation* or phenomenon and suggesting potential holistic approaches for action moving forward [119].

The idea of a *situation* is central to the pragmatist and interdisciplinary approach in my thesis. A *morally problematic situation* refers to more than just a narrow ethical question to be 'solved' [117, 120]. It refers to a complex and holistic account of many related elements – from the teratogenic effects of alcohol on neurodevelopment, to factors influencing clinical practice and judgement (like stigma, as I explore below), to the social construction of a diagnosis such as FASD, and related moral panic about women's role in society – leading to a plurality of ethical individual and society-wide responses. As I explore further in Chapter 8, the lived experiences of key FASD stakeholders can help us to understand the everyday ethical challenges that arise in the lives of stakeholders [118], and only by becoming aware of these challenges can we begin to address and redress them holistically [48]. Racine, in his "integrative pragmatist approach to moral problem solving," describes an iterative and deliberative process to inform responses [117, 120]: 1) becoming aware of a *morally problematic situation* (e.g., through intuition, conflict, tension); 2) deliberating and analyzing that situation to generate; 3) an ethical response, which can then be; 4) evaluated in terms of outcomes leading to; 5) moral growth – where a new equilibrium has been reached among "competing interests and principles" [120]. My thesis serves as an example of the first two elements – i.e., becoming aware of the *situation* of FASD (Chapters 3-5 and 7) and deliberating (with participants) on potential responses (Chapter 6).

Pragmatism and FASD discourse

In my thesis, these pragmatist assumptions inform several methodological choices and the overall direction of my work. Beyond asserting that lived experiences can help ground responses to everyday ethical challenges and *situations*, the concept of epistemic injustice can also help justify the need to include stakeholder knowledge and experiential data in moral reasoning. Some scholars, including feminists and pragmatists, describe epistemic injustice in terms of testimonial injustice (i.e., an individual's knowledge claims are rejected due to prejudice or perhaps stigma) and hermeneutical injustice (i.e., when a society's language and concepts do not reflect the experiences of entire groups of people, perhaps due to their exclusion from shaping public knowledge) [48]. As I explore throughout my thesis, many different stakeholders involved in FASD (from marginalized women to people with disabilities) have historically been excluded from knowledge production and dissemination, making this work even more urgent.

Ultimately, while my work is not action research *per se* [121], it aims in that direction (i.e., it is interdisciplinary, situationalist, experiential, and action-oriented). To discuss and approach the normative dimensions of FASD, alcohol, and pregnancy (e.g., which public health message(s) should we communicate about alcohol and pregnancy given concerns about stigma and birth mothers), we need a detailed understanding of the *situation* – i.e., what is the actual context of FASD, alcohol, and pregnancy in Canada. We chose to centre the voices of key stakeholders like people with FASD, not only to understand their views empirically, but to work toward improving their *situations*. In thinking about the *situations* of FASD stakeholders and sources of challenges, we began to explore theories of stigma and the process of stigmatization.

Conceptualizing Stigma: Link and Phelan's model

Stigma and processes of stigmatization have been objects of academic study for decades across numerous disciplines, perhaps most famously described by sociologist Erving Goffman in his seminal 1963 text titled *Stigma: Notes on the management of spoiled identity* as the "situation of the individual who is disqualified from full social acceptance" [122]. Given my project's focus on uncritical or hyperbolic news coverage, I have been primarily concerned with the potential negative impact of exaggerated and stereotyped narratives about marginalized groups – narratives that could lead to the "spoiling" of identity and, ultimately, to discrimination. In this work, marginalized groups could include individuals with FASD, members of their family (in particular, their birth mothers), and any other relevant groups tied to FASD-associated stereotyped (e.g., Indigenous groups and stereotypes regarding alcohol consumption [123]).

In my thesis, I employ a more recent definition of stigma from Link and Phelan's seminal 2001 paper titled *Conceptualizing Stigma* [50], in part because their approach appears consistent with pragmatist assumptions (i.e., they combine theory and observations from sociology and social psychology as a foundation for their model). They define stigmatisation as a process requiring five co-occurring elements: 1) labelling differences perceived as non-trivial in a given context/society (e.g., race, gender, disability); 2) the attribution of stereotypes to those labels; 3) a process of othering based on labelled stereotypes; 4) discrimination resulting from labelling, stereotyping, and othering; where 5) various forms of power align against that group.

In our research, we sought evidence of these five dimensions of stigma in news coverage, attending most to stereotyped representations of FASD, alcohol, and pregnancy. In the focus group project that built on the results of our media analysis, we designed interview questions reflecting concerns about labelling difference (i.e., tied to diagnostic labels) and stereotypes associated with FASD, alcohol, and pregnancy, which additionally provided experiential data that reflect other elements of this model (i.e., othering). Categories associated with disability have long been studied in media, tied to concerns about labelling and stereotyping – an important reason we drew on work in Disability Studies. Notably, recent empirical and theoretical work has also begun to emerge on the link between stigma and FASD [49, 87, 88, 124-130].

Disability studies: What does disability mean and what stories do we tell?

Disability studies, as a formal academic discipline, emerged in the early 1980s in response to and as part of disability activism [131]. A core goal of disability studies has been to problematize common understandings of concepts like disability and impairment [132] through the development of different models to help frame and shape discourse on these topics. An early relevant definition of disability comes from an activist group in the UK called the "Union of the Physically Impaired Against Segregation". In 1975, they argued that "…it is society which disables [us]. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society" [131]. Mike Oliver, in the early 1980s, operationalized this definition as the "social model of disability" in the social work literature [133]. The social model of disability suggests that disability is not something located in a person's body or mind, but in an unaccommodating society and environment [134]. The social model of disability contrasts an individual, medical, or deficit model: a model reflecting the implicit and uncritical ways the average person may think about disability; a model put forward by disability scholars to describe common ways of understanding and engaging with disability.

Disability studies and FASD

There are two main ways in which disability studies theory has informed my research. First, in a broad sense, re-conceptualizing impairment and disability in terms of environmental and social barriers, rather than just as bodily difference, informed the questions I asked and the approaches I took to interpreting my participants views. Most of my participants discussed both what they felt was ‘wrong with them’ as well as what is ‘wrong with others’ in terms of negative or discriminatory attitudes. Second, in a narrower sense, a sub-segment of disability studies and sociology of disability scholarship has explicitly explored media discourse, representation, and stereotyping [34]. These empirical works have identified common stereotyped narratives in news coverage, portrayals in fiction, and more [35]. In our analysis (see Chapter 4), we identified common disability tropes present and relevant to coverage of people with FASD in Canada.

Feminist bioethics: Paying attention to power dynamics

Pragmatist bioethics and philosophy share concerns and approaches with feminist philosophy, ethics, and bioethics [135], including attention to context [136]. However, feminist theory focuses more directly on identity-oriented contextual factors influencing differences in power across both relationships and institutions. For example, the concept of relational autonomy [137] recognizes how choice can be constrained or enhanced by connections to the people around us (e.g., supportive or abusive partners, implicit biases influencing doctor-patient relationships) – connections informed by institutional forces tied to gender, ability, race, and more (sometimes referred to in the context of feminist frameworks such as intersectionality [138, 139]). Other feminist analyses explore gendered policy influencing outcomes for different groups of people (e.g., public health messaging around alcohol and pregnancy).

The projects I undertook for my thesis necessarily contained a gendered component: health advice, public attitudes, and public policy associated with alcohol consumption during pregnancy directly implicate and impact women more than men. Women often bear the burden of stigma and responsibility associated with alcohol and pregnancy, and public health messaging often focuses on how women ought to behave. Consequently, it follows that we bring to bear a feminist lens on these challenges, complementary to pragmatist ethics and disability studies.

From methodology to methods in practice

With these methodologies, theoretical orientations, and concepts clarified, we can now turn to the specific research methods we used to implement this vision and to ask our questions.

Methods: Media content analysis

Media content analysis [140], a kind of mixed-methods thematic content analysis, can combine both quantitative and qualitative methodologies to improve reliability and rigour while remaining open to the depth of qualitative data [141]. Notably, mixed-methods research aligns well with a pragmatist epistemology/ontology: “Pragmatism… sidesteps the contentious issues of truth and reality, accepts, philosophically, that there are singular and multiple realities that are open to empirical inquiry and orients itself toward solving practical problems in the ‘real world’” [142]. This kind of analysis also attends to evolving media messages over time, location, and source. With the quantitative component, we described media information by systematically applying a strictly defined coding guide to the sample, and by counting occurrences of identified themes. We also assessed intercoder reliability in percent agreement, to ensure the validity of coded themes. Drawing from the qualitative component, we gained a richer understanding of the media’s meanings. As described by Atwood-Gailey [143], this kind of media analysis draws on at least two theories of communication: “(1) a cultural studies approach that views the news media as a symbolic system that both structures and is structured by society… and (2) framing theory…, which provides insights on the media’s role in the social construction of reality by wedding journalists’ specific language selections to larger cultural values, beliefs, and practices”. For a detailed account of the application of this method, please refer to Chapters 3 and 4.

Methods: Focus group interviews

To build on both the quantitative and qualitative components of media content analysis, we conducted in-depth qualitative focus group interviews across multiple distinct stakeholder groups (i.e., using a multi-stakeholder focus group design). This study design enabled us to explore participants' perspectives, beliefs, and constructed meanings [144, 145], and to shed light on areas and layers of tension discovered within media discourse. Additionally, focus group interviews may be considered more 'natural' settings for discussion than one-on-one interviews, in part because the group dynamic could help participants express themselves [144]; participants may be more comfortable expressing themselves in solidarity with people who have similar life experiences than directly to a researcher. We chose this method in contrast to other, discarded options such as surveys or one-on-one interviews. Surveys would have provided data of insufficient depth, allowing us to inquire only into *what* attitudes people hold without being able to gauge *why* they hold them. One-on-one interviews, while providing the depth required, would not have feasibly enabled us to pursue a multitude of distinct stakeholder perspectives. Finally, in line with pragmatic approaches to understanding and addressing difficult situations, focus groups enabled our participants to deliberate together, to seek common understandings of complex topics, and to build various forms of consensus on how to move forward. For a detailed account of the application of this method, please refer to Chapters 5 and 6, as well as Chapter 7.

Conclusion

Ultimately, my work is rooted in the assumption that media can both affect and reflect public understanding. With a specific focus on neuroscience news coverage building on existing neuroethics scholarship, the questions we asked and the methods we implemented (i.e., media content analysis and focus group interviews) were grounded in Link & Phelan's model of stigma and pragmatist approaches to bioethics. My thesis was heavily informed by work in disability studies (i.e., the social model of disability, disability media stereotypes) and feminist bioethics (i.e., critiquing gendered assumptions and expectations of women and mothers in the context of alcohol use during pregnancy), key lenses through which I understood and interpreted our data.

SECTION OVERVIEW: Media content analysis: Chapters 3 and 4

Chapters 3 and 4 contain published manuscripts that address Objective 1: To understand information presented to Canadians in print news media about FASD, alcohol, and pregnancy. These articles represent two distinct slices of the same dataset that, when taken together, tell one larger story. In Manuscript I (Chapter 3), titled "*Stigmatisation, exaggeration, and contradiction: An analysis of scientific and clinical content in Canadian print media discourse about fetal alcohol spectrum disorder,"* we analyzed health and science information associated with news coverage of FASD, alcohol, and pregnancy. We engaged directly with bioethics arguments and medical literature, assessing concerns about accurate, ethical, and stigmatizing science communication, to explore areas in which discourse could (mis)inform, confuse, or inflame public debate about sensitive health-related topics. In Manuscript II (Chapter 4), titled "*Stereotyping and stigmatising disability: A content analysis of Canadian print news media about fetal alcohol spectrum disorder,"* we connected coverage of the lived experience of FASD, alcohol, and pregnancy to disability studies and feminist literatures. We assessed common narratives and stereotypes permeating media coverage of disability to qualify how FASD, and women who drink while pregnant, have been portrayed. Additionally, we explored the construction of – and social expectations associated with – motherhood as they relate to alcohol consumption during pregnancy, and the history of the FASD diagnosis. Although Manuscript I was written before Manuscript II, it was published later. Engaging with separate literatures across distinct parts of a dataset enabled us to bring our data into conversation with additional points of view, exploring nuances and facets of news coverage about both a medical diagnosis/health information and groups of marginalized people.

CHAPTER THREE – CHALLENGES ASSOCIATED WITH SCIENCE AND HEALTH NEWS COVERAGE OF FASD, ALCOHOL AND PREGNANCY

Manuscript I: Stigmatisation, exaggeration, and contradiction: An analysis of scientific and clinical content in Canadian print media discourse about fetal alcohol spectrum disorder

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Abstract

Background*:* Fetal alcohol spectrum disorder (FASD), a complex diagnosis that includes a wide range of neurodevelopmental disabilities, results from exposure to alcohol in the womb. FASD remains poorly understood by Canadians, which could contribute to reported stigma faced by both people with FASD and women who drink alcohol while pregnant. ***Methods*****:** To better understand how information about FASD is presented in the public sphere, we conducted content analysis of 286 articles from ten major English-language Canadian newspapers (2002-2015). We used inductive coding to derive a coding guide from the data, and then iteratively applied identified codes back onto the sample, checking inter-coder reliability. ***Results*****:** We identified six major themes related to clinical and scientific media content: 1) prevalence of FASD and of women's alcohol consumption; 2) research related to FASD; 3) diagnosis of FASD; 4) treatment of FASD and maternal substance abuse; 5) primary disabilities associated with FASD; and 6) effects of alcohol exposure during pregnancy. ***Discussion*****:** Across these six themes, we discuss three instances of ethically consequential exaggeration and misrepresentation: 1) exaggeration about FASD rates in Indigenous communities; 2) contradiction between articles about the effects of prenatal alcohol exposure; and 3) scientifically accurate information that neglects the social context of alcohol use and abuse by women. Respectively, these representations could lead to harmful stereotyped beliefs about Indigenous peoples, might generate confusion about healthy choices during pregnancy, and may unhelpfully inflame debates about sensitive issues surrounding women's choices.

Keywords**:** Fetal alcohol spectrum disorder; FASD; stigma; alcohol and pregnancy; disability; science communication; Indigenous; Canada

Résumé

Contexte **:** L’ensemble des troubles causés par l’alcoolisation fœtale (ETCAF), un diagnostic complexe qui comprend une vaste gamme de troubles neurodéveloppementaux, résulte de l’exposition à l’alcool dans l’utérus. L’ETCAF demeure mal compris par les Canadiens, ce qui pourrait contribuer à la stigmatisation dont souffrent les personnes atteintes d’ETCAF et les femmes qui consomment de l’alcool pendant leur grossesse. ***Méthodes*** **:** Pour mieux comprendre comment l’information sur l’ETCAF est présentée dans la sphère publique, nous avons analysé le contenu de 286 articles tirés de dix grands journaux canadiens de langue anglaise (2002-2015). Nous avons utilisé le codage inductif pour établir une grille de codage à partir des données, puis nous avons appliqué de façon itérative des codes identifiés sur l’échantillon, en vérifiant la fiabilité intercodeurs. ***Résultats*** **:** Nous avons identifié six grands thèmes liés au contenu cliniques et scientifiques des médias : 1) prévalence de l‘ETCAF et de la consommation d’alcool chez les femmes ; 2) recherche en lien avec l’ETCAF ; 3) diagnostic d’ETCAF ; 4) traitement de l’ETCAF et de l’abus de substances par les mères ; 5) incapacités primaires associés à l’ETCAF ; et 6) effets de l’alcool pendant la grossesse. ***Discussion*** **:** Dans le cadre de ces six thèmes, nous examinons trois types d’exagération et de fausse représentation qui ont des conséquences sur le plan éthique : 1) l’exagération des taux d’ETCAF dans les communautés autochtones ; 2) la contradiction entre les articles sur les effets de l’exposition prénatale à l’alcool ; et 3) l’information scientifiquement exacte qui néglige le contexte social de la consommation et de l’abus d’alcool par les femmes. Respectivement, ces représentations pourraient mener à des croyances stéréotypées préjudiciables au sujet des peuples autochtones, pourraient créer de la confusion quant aux choix sains pendant la grossesse et risqueraient d’enflammer inutilement les débats sur des questions délicates concernant les choix des femmes.

***Mots-clés* :** ensemble des troubles causés par l'alcoolisation fœtale; ETCAF; stigmatisation; alcool et grossesse; incapacité; communication scientifique; Autochtones; Canada

Introduction

Fetal alcohol spectrum disorder (FASD), a complex diagnosis that spans a wide range of neurodevelopmental disabilities affecting roughly 1 in 100 Canadians [1], results from alcohol exposure in the womb. A heterogeneous and difficult-to-diagnose disorder, FASD presents in myriad ways, including with characteristic facial features (e.g., thin upper lip, no philtrum), and with disabilities in executive function (e.g., hyperactivity, impulse control), cognition (e.g., low IQ, learning difficulties), and other brain domains (e.g., motor function, language, mood regulation) [2, 3]. Previous diagnostic guidelines included diagnoses like fetal alcohol syndrome (FAS), partial FAS, and alcohol-related neurodevelopmental disability [2], but more recent guidelines have simplified the diagnosis into the following categories: 1) FASD with sentinel facial features; 2) FASD without sentinel facial features; and 3) an at-risk category [3].

Although more recent studies indicate that the prevalence of FASD could prove higher than 1 in 100 (i.e., as high as 2-5 in 100 in the US and some European countries) [4], it remains a largely "invisible disability": only about 10% of people diagnosed with FASD present with identifiable physical features [5]. Compounding the issue, survey data indicate that while most Canadians know that FASD exists (86%) and that drinking alcohol when pregnant can harm a fetus (76%), they provide less accurate descriptions of its signs and symptoms [6-8]. This lack of public knowledge could indicate that sources other than exposure or personal experience, such as the news media, could be important for the public's understanding of FASD. They could also be sources of stigmatisation for people with FASD and women who drink while pregnant.

Stigmatisation, a process of negative stereotyping causing discrimination [9], remains a tremendous social challenge and a barrier to the wellbeing of marginalized groups. Link and Phelan [9] describe this process as one where certain identified differences between groups become fodder for stereotyping, othering, and discrimination – in a context where various forms of power align against the group in question. As an example, some people with FASD report experiencing problems ranging from social exclusion to employment discrimination [10, 11]. In addition, since FASD results from alcohol exposure in the womb, some women who drink alcohol during pregnancy can also face stigmatisation [12]. This stigma might be exacerbated by judgmental public discourse and health messaging that emphasize individual blame and responsibility [13], and which stereotype women who drink while pregnant as unfit – or even criminally negligent – mothers [14].[1]

Public discourse could be one potential factor contributing to the stigmatisation of people with FASD and women who drink while pregnant – especially given the media's long history of misrepresenting and stereotyping people with disabilities (e.g., as victims, as villains, as superhuman) [17]. Broadly speaking, since the mass media are thought to both reflect and impact public attitudes and opinions [18], this could include how the public perceives and constructs identities around issues such as health and disability. As we will discuss later in this paper, these perceptions can also include Indigenous identities and stereotypes surrounding alcohol use.

Previous media studies exploring discourse related to FASD in the US, the UK, and Australia indicated a larger media focus on the implications of alcohol use during pregnancy than on stories about the lives of people with FASD [14, 19, 20]. This was sometimes by design [21]; however, even when FASD itself was the primary focus of a study, pregnant women and issues

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[1] In some jurisdictions in the US, the use or abuse of certain substances during pregnancy, including alcohol, can be used as evidence of crimes that include child abuse and neglect [15]. These approaches have not yet materialized in the Canadian context [16].

of alcohol consumption usually came to the fore – including in study discussion sections. Ultimately, these articles identified common narratives framing women who drink while pregnant as dangerous, blameworthy, and irresponsible, as well as discussions about how women should behave when pregnant [14]. In contrast, FASD was framed as a crisis [21], with occasional stories about people with FASD who were "blameless victims" of their mothers' drinking [19, 20], or occasionally as themselves victimizing others [14]. To the best of our knowledge, no research has characterized media coverage about FASD in Canada. Accordingly, to gain deeper insight into the kind of information the public receives about FASD, which could inform public attitudes toward individuals with the disorder as well as women who drink while pregnant, we conducted an analysis of the FASD-related content found in Canadian media.

Methods

In this study, we employed a qualitative media content analysis approach [22], similar to several previous media studies [23-25]. We reported these methods in full in an article about the social dimensions of discourse identified during the same content analysis, some of which is reprinted here or else is specific to this manuscript [26].

Sample

Using the Factiva news database, we searched for English and French print news articles published in Canada between January 1st 2002 and October 31st 2015. We searched for the following keywords in headlines and lead paragraphs: "("fetal alcohol spectrum disorder" OR "FASD" OR "fetal alcohol syndrome" OR ("alcohol" AND "pregnancy") OR "ensemble des troubles causés par l'alcoolisation foetale" OR "ETCAF" OR "syndrome d'alcoolisation foetale" OR ("grossesse" AND "alcool"))". We restricted our search to 10 of the most-distributed Canadian print news sources [27], all of which are available electronically: *The Toronto Star* (n=20), *The Globe and Mail* (n=22), *The Montreal Gazette* (n=11), *The Vancouver Sun* (n=30), *The Vancouver Province* (n=6), *The National Post* (n=11), *The Winnipeg Free Press* (n=100), *The Calgary Herald* (n=32), *The Ottawa Citizen* (n=13), and *The Edmonton Journal* (n=41). Note that more than one third of this sample (100/286 articles) came from The Winnipeg Free Press, which won a 2010 Canadian Institutes of Health Research (CIHR) grant to specifically cover FASD and its "causes, social costs, treatments, and prevention" [28].[2]

Of the rest of the articles, more than a third came from the other Western provinces (British Columbia and Alberta – no newspaper from Saskatchewan was included). In total, almost three quarters of the sample came from these three Western provinces, with only 27% (77/286 articles) coming from Ontario, English Quebec news, or national papers like The Globe & Mail. We had to exclude *Le Journal de Montréal*, *La Presse*, *Le Journal de Québec,* and *The Toronto Sun* because Factiva only began archiving these sources in 2011. See Figure 1 for more information about the distribution of the sample by year/source.

Coding Process

Three coders used a random sample of 25 articles to develop a coding guide inductively, capturing key areas of content present in the sample. The coding guide was then systematically applied to the remainder of the sample. This process was repeated through several sample updates and coding guide refinements. We assessed intercoder reliability for each code through each iteration, discarding six codes and five sub-codes with a percent agreement below 0.75.

Coding Guide

We coded 286 articles for coverage of three broad categories: 1) scientific content; 2) clinical content; and 3) social content. This article reports on the six codes (and fifteen sub-

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[2] This article was included in the sample. In addition, given these funds, the coverage was typically more nuanced and in depth than other coverage, despite the somewhat sensational series title "Wounded in the Womb".

codes) in the scientific (See Table 1) and clinical (See Table 2) categories. Scientific content reflects scientific knowledge about FASD as reported by the media (e.g., research related to FASD). Clinical content reflects clinical care for people with FASD (e.g., diagnosis of FASD) and mothers (e.g., treatment of maternal substance use), as well as descriptions of what FASD entails symptomatically (i.e., primary disabilities associated with FASD). The 'Effects of alcohol exposure during pregnancy' code, categorized in clinical content, has also been further broken down into four categories beyond the parameters defined in the coding guide to gain deeper insight into this particularly complex area of discourse. Another article reported on the findings of the social content code since there are too many data to report in a single article, and the data in that content category provide opportunities to engage with different literatures [26].

Results

We identified six major themes, or content areas corresponding to our codes, broken down across fifteen sub-themes (sub-codes), with the most frequent being descriptions of the primary disabilities associated with FASD (48%, n=136), and prevalence of FASD and of women's alcohol consumption (46%, n=131). Tables 1 and 2 describe the coding structure in detail, and explain the scope of each code and sub-code (with pertinent examples). After each table, we elaborate on some of the more complex and multidimensional codes, which require more space for elaboration than the table can provide (i.e., a richer unpacking of the content found in the 'diagnostic challenges' sub-code than seen in Table 2), with illustrative in-text examples provided to exemplify important nuances of the content. When providing quotes, both in text and in the tables, we reference each article by newspaper and year, to avoid singling out any given journalist, while maintaining transparency on data sources. We do not include these sources in the References section, as they are data.

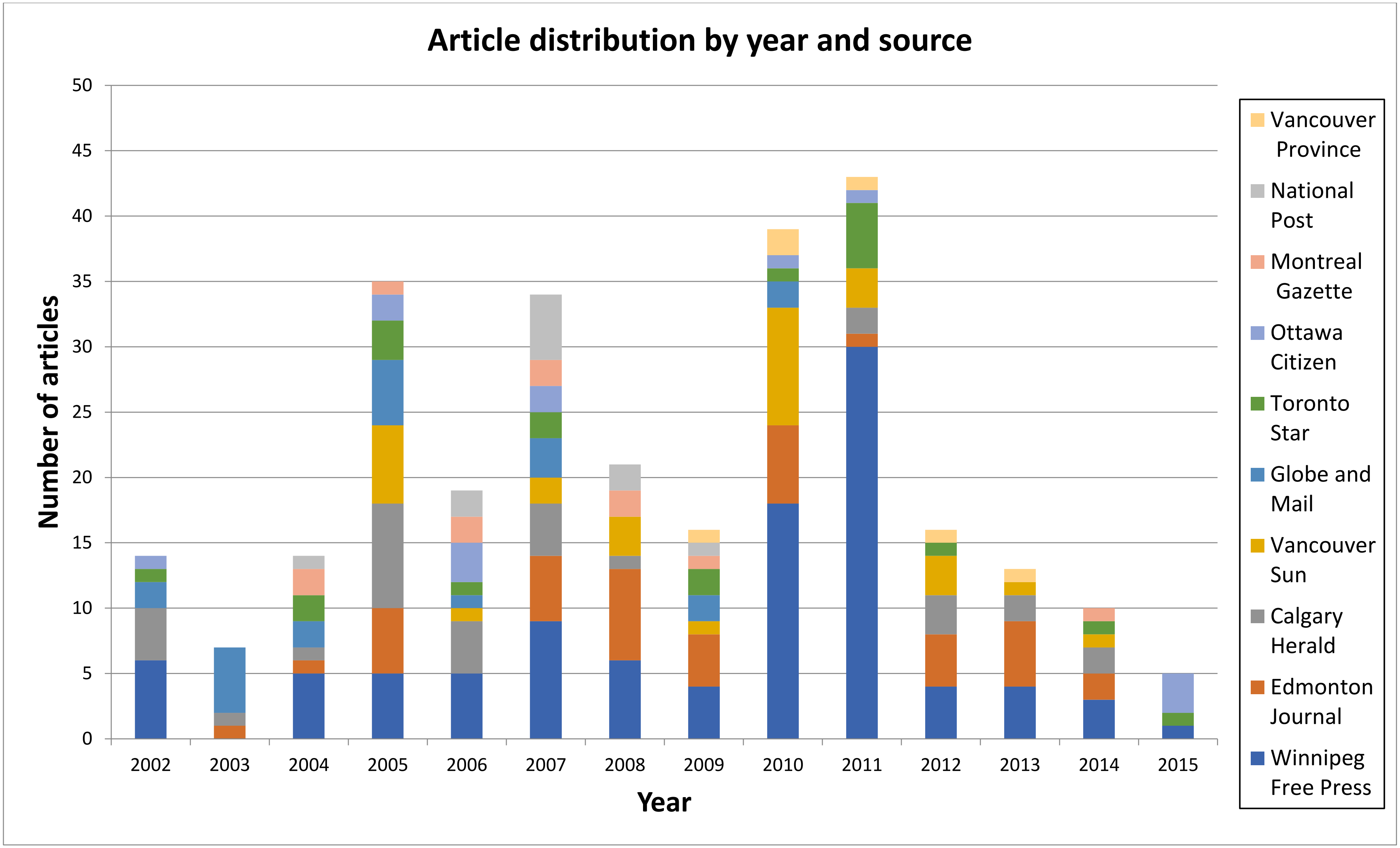

Figure 1: Stacked bar graph indicating the distribution of articles across the sample, sorted by year and by source. The colour legend for sources and the stacked bars themselves are organized in ascending order, from the Winnipeg Free Press at the bottom (n=100) to the Vancouver Province on the top (n=6). Figure reprinted with permission from [26].

A. SCIENTIFIC CONTENT

Table 1 – Scientific Content Results: Coding Structure and Examples

Code	Sub-code	Scope	% of sample, # of articles	Examples
Prevalence of FASD and of women's alcohol consumption		Article reports on FASD prevalence, or on alcohol consumption rates in different groups of women.	46%, n=131	
	General Population	Article reports on FASD prevalence across all ages around the world, but mainly in Canada's Western provinces.	35%, n=99	"It's estimated that there are more than 36,000 Albertans with FASD" (Edmonton Journal 2014).
	Uncertainty	Article reports a lack or insufficiency of current FASD prevalence estimates.	14%, n=39	"There are no clear numbers to determine how many people are living with FASD in Manitoba" (Winnipeg Free Press 2006) and "A relatively new paper… says all the best estimates are lowballed" (Winnipeg Free Press 2011).
	Criminal justice system	Article reports on FASD prevalence in the criminal justice system. Includes proportion of offenders with FASD, and proportion of people with FASD behaving criminally.	11%, n=32	"A study of 91 inmates… found 10 per cent have some form of fetal alcohol spectrum disorder -- 10 times the incidence in the general population" (Calgary Herald 2007).
	Indigenous Populations	Articles reports on FASD prevalence in Indigenous populations in Canada.	8%, n=24	"Among aboriginal people, the prevalence of FAS is much higher than the national average—as high as 10 per cent in some communities where alcohol abuse is widespread" (The Globe and Mail 2005).
	Child welfare system	Articles reports on FASD prevalence in the child welfare system. Includes proportion of kids in the system with FASD, and proportion of kids with FASD in the system.	5%, n=14	"Another study indicated that 80 per cent of FASD-affected individuals are [raised] by adoptive parents or through foster care" (Ottawa Citizen 2006)".

	Women's alcohol consumption	Article reports on the prevalence of pregnant women's alcohol intake. Also includes discussions about drinking in relation to unplanned pregnancies, or rates of women who consume alcohol in general.	5%, n=14	"In 2003, about 12 per cent of women in Winnipeg admitted to consuming alcohol while expecting. In 2008, that number inched up to 14 per cent" (Winnipeg Free Press 2011)
Research related to FASD		Article reports research into any dimension of FASD. Excludes examples with no research findings.	26%, n=73	
	Diagnosis and screening	Article reports research on novel diagnostic or screening tool/methods. Includes screens in subgroups (e.g., criminal justice system).	9%, n=26	"…a simple test that tracks eye movements may offer a new tool to accurately diagnose fetal alcohol syndrome" (Edmonton Journal 2005).
	Treatment and Prevention	Article reports research into novel treatments for FASD itself, or novel prevention methods ('treating fetuses').	6%, n=18	"… aboriginal researchers had to consider a number of questions when designing programs to prevent FASD, including: How would you approach a woman in the community?" (Vancouver Sun 2006)
	Levels of prenatal alcohol exposure	Article reports research findings connecting levels of prenatal alcohol exposure to FASD outcomes (see text).	5%, n=15	"The University of Pittsburgh recently released findings from a study following 565 mothers and children since 1982, when the women were all four months pregnant. Even children whose mothers drank less than 1.5 drinks a week during pregnancy were a few pounds smaller as adolescents" (The Globe and Mail 2003)
	Primary disabilities	Article reports on research into specific disabilities and symptoms that may appear in cases of – or help identify – FASD.	2%, n=5	"Writing in the journal Alcoholism: Clinical and Experimental Research, researchers say their findings indicate that deficits in so-called eye-blink conditioning, or EBC, can identify children with probable fetal alcohol syndrome." (Vancouver Sun 2008).

Prevalence of FASD in the general population – Societal burden and public health concerns

Prevalence was sometimes used to frame FASD as a burden on society, e.g., "…it's estimated that at least one child is born with fetal alcohol syndrome each day in Canada, with the lifetime costs of caring for such children estimated at $1.4 million" (Edmonton Journal 2007). In addition, a focus on the need to decrease FASD prevalence was associated with public health concerns, e.g., "Brain damage from alcohol exposure in the womb is the leading preventable cause of mental retardation in the Western world" (Globe and Mail 2010). Notably, FAS prevalence was sometimes conflated with FASD prevalence – e.g., "…[FAS], a developmental disorder that affects about one in every 100 Canadian children" (Vancouver Sun 2005), "about one in 100 people have FASD" (Winnipeg Free Press 2010) – with only a few articles making the distinction, e.g., "Health Canada estimates nine in every 1000 babies born here have FASD; one to three of those babies will have full [FAS]" (Calgary Herald 2005).

Research related to FASD: Levels of prenatal alcohol exposure – Inconsistent definitions, findings, and variables across the sample

Many articles used the amount of alcohol consumed while pregnant as a stand-in for prenatal alcohol exposure. Definitions of these amounts differed across the sample, as in the case of 'light drinking', e.g., "… light drinkers had a mean consumption of a drink a week" (Winnipeg Free Press 2002), "light drinking during pregnancy says one study… found detectable 'deficits'… at exposure levels of less than one drink a day" (Edmonton Journal 2007); however, a few articles explicitly commented on this confusion, e.g., "…people tend to vary in what is considered light drinking" (Winnipeg Free Press 2010). In addition, the definition of a standard drink differed between reports, e.g., "355 mL of beer or 118 mL of wine" (Calgary Herald 2006), "175 [ml] of wine… or just under a pint of beer" (Vancouver Sun 2009). Articles also presented inconsistent findings across the sample, suggesting that light drinking 1) caused harm, e.g., "[children] whose mothers drank even lightly were shorter, lighter and had smaller head circumferences" (The Globe and Mail 2003); 2) caused no harm, e.g., "light drinking is fine" (Vancouver Province 2013); or 3) was potentially beneficial, e.g., "… [babies of mothers who drank lightly] were markedly less likely to demonstrate behavioural problems" (Winnipeg Free Press 2010). The articles that reported potential benefits of alcohol all pointed to a British study first published online in 2010 [29]. Finally, the variables measured to indicate harm varied between studies, and included anything from physical features – e.g., "detectable 'deficits' in height…" (Edmonton Journal 2007) – to behavioural features, e.g., "3.2 times more likely to have behaviour and aggression problems" (Montreal Gazette 2007).

B. CLINICAL CONTENT

Table 2 – Clinical Content Results: Coding Structure and Examples

Code	Sub-code	Scope	% of sample, # of articles	Examples
Diagnosis of FASD		Article reports on FASD diagnosis. Includes examples from Research related to FASD sub-code on diagnosis and screening.	20%, n=58	
	Diagnostic Challenges	Article reports on real-world challenges in diagnosing FASD. Includes discussions about misdiagnosis (see text).	19%, n=55	"But it's often an invisible brain injury, difficult to diagnose and masked by articulate speech and regular appearance" (Ottawa Citizen 2015).
	Diagnostic Process	Article reports on different elements of the FASD diagnostic process. Includes both medical and logistical processes.	8%, n=24	"Everyone from defence lawyers to judges to probation officers can refer a youth to the program, where a team of co-ordinators does an initial screen… even tracking down biological mothers to ask if they drank…" (Edmonton Journal 2010).
	Diagnostic Criteria	Article reports explicit and clear features of FAS (not FASD) that may lead to diagnosis.	2%, n=6	"Physicians make the diagnosis of FAS in children who exhibit a small head, characteristic features of the face and cognitive and neurological abnormalities" (Winnipeg Free Press 2002).
Treatment of FASD and maternal substance abuse		Article reports on treatments for elements of FASD, or, in a minority of cases, alcohol addiction for pregnant women. The latter case does not necessarily reflect a causal connection between addiction and FASD, but rather, one target for treatment in the context of our sample (which included the term "alcohol and pregnancy", independent of FASD). Includes interventions for features of FASD. Includes examples from	28%, n=80	"The Ministry of Education is trying to change attitudes and help students with FASD succeed in school through the Provincial Outreach Program for FASD…" (Vancouver Sun 2010).

		Research related to FASD sub-code on treatment and prevention.		
Primary disabilities associated with FASD		Article reports on features, symptoms, or disabilities associated with FASD. Includes examples from Research related to FASD sub-code on primary disabilities. Excludes social concerns sometimes described as secondary disabilities (e.g., homelessness).	48%, n=136	
	Cognitive and behavioural features of FASD	Article reports examples of primary social, behavioural, cognitive, & emotional features of FASD. Includes broad range of features, categorized differently across articles.	42%, n=121	"The consequence of these physical changes can be profound… impairment of fine motor skills, hearing loss, ability to coordinate gait and hand-eye functions. From these deficits cascade a host of others… Subsequent learning difficulties involve poor capacity for abstract thought, which limits development of mathematical and language skills, all compounded by problems with memory, attention span and poor judgment" (The Vancouver Sun 2005).
	Physical features of FASD	Article reports examples of primary physical features of FASD. Includes facial features, and growth, organ, and sensorimotor issues.	28%, n=80	"…a very thin upper lip and no groove between the upper lip and nose" (Calgary Herald 2012), "Other defects include malformation of such organs as the heart, liver, and kidneys. Vision and hearing problems…" (Montreal Gazette 2008)
Effects of alcohol exposure during pregnancy		Article reports on concerns about the impact of different variables related to alcohol consumption on FASD outcomes (see text). Includes examples from Research related to FASD sub-code on levels of prenatal alcohol exposure. Note that in text, four further subdivisions are reported that were not assessed for inter-coder reliability.	19%, n=55	"'I have patients who think a couple of beers a day is not an issue. And the question is, is it an issue? That's what we're going to look at,'… She said one doctor may tell a pregnant woman, or one trying to get pregnant, 'don't drink at all,' while another may say 'moderate drinking' is OK. (Edmonton Journal 2009).

Diagnosis of FASD: Diagnostic challenges – Medical, healthcare systems, and social barriers

A main challenge identified was the issue of delaying or missing diagnosis, and its consequences, e.g., “Being misdiagnosed can have serious lifelong effects because children miss out on specialized therapy” (Vancouver Sun 2005). Otherwise, three broad kinds of challenges were reported: 1) medical barriers; 2) healthcare system barriers; and 3) social barriers.

Medical barriers included issues like difficulty identifying and defining features across a wide spectrum of disabilities, e.g., “Because it’s a spectrum disorder, effects can range from very subtle to full-blown and intense. You don’t know what you’re dealing with” (Calgary Herald 2005), or a lack of appropriate tests.

Healthcare system barriers included issues like lengthy waitlists, difficulty accessing diagnostic services based on location (e.g., “…and many kids in rural and remote communities never get diagnosed” (Winnipeg Free Press 2010)) or age (e.g., “…only children can get a diagnosis…. Adults are out of luck.” (Winnipeg Free Press 2013)), or limited resources (e.g., “If resources were available, justice staff say they could send five times that many kids with suspected FASD to the clinic” (Edmonton Journal 2010)).

Social barriers included issues like possible racial biases (e.g., “FASD is also seen as an aboriginal disease, so it goes under-reported among non-aboriginals” (Winnipeg Free Press 2011)), or a reluctance to report drinking while pregnant (e.g., “‘Researchers say the number is an underestimate because… mothers […] fear the stigma from admitting they drank alcohol while pregnant’” (Ottawa Citizen 2015)).

Treatment of FASD – Early social interventions for people with FASD and at-risk women

For the treatment of people with FASD, an emphasis was placed on early interventions, e.g., “The sooner a baby is properly diagnosed, the faster special social and education services can be provided" (Montreal Gazette 2006). Most discussed interventions had social goals, like stopping criminal behaviour, e.g., "The… FASD program is designed to aid youths with the disorder before their troubles either land them in jail or in harm's way" (Winnipeg Free Press 2006). Very few articles mentioned biomedical treatments. The few options mentioned were speculative or novel, e.g., "…vitamin A could act almost like an antidote to the effects of alcohol on very early embryos…" (Edmonton Journal 2011). While most articles discussing the treatment of at-risk women focused on treating alcoholism, a few editorials suggested extreme measures that included criminalization and forced interventions, e.g., "These doped-up druggies should be sterilized after the second child…" (Calgary Herald 2005).

Effects of alcohol exposure during pregnancy

Alcohol consumption – Abstention advice and uncertainty

Many articles mentioned that a) women should not drink alcohol when pregnant (e.g., "The best advice is to abstain from alcohol while expecting a baby" (Calgary Herald 2006)) or that b) alcohol is never safe for pregnant women (e.g., "But [the doctor] stressed modern evidence shows no amount is safe" (Toronto Star 2015)). Additionally, several articles discussed uncertainty about the link between alcohol and FASD outcomes, with a few framing uncertainty as the reason for advising abstinence, e.g., "[She] is correct that no one knows what amount of alcohol during pregnancy is safe. That's why [many organizations] recommend that the most prudent choice for women who are pregnant is to abstain from alcohol" (Ottawa Citizen 2002).

Alcohol consumption – Cross-border debates about harmful amounts

Many articles mentioned how much drinking can harm a fetus, e.g., "A number of studies have linked heavy drinking on a regular basis during pregnancy to stunted growth, birth defects and brain development problems" (National Post 2007). These articles described harm as caused by: 1) heavy drinking, 2) single or occasional binges, 3) drinking in moderation or moderate amounts, 4) light drinking, and 5) a single drink.

In contrast, several of these articles discussed British research and policy contradicting advice that any amount of alcohol is harmful: "…it's safe to drink a little bit of alcohol during pregnancy… experts have concluded 'no consistent evidence' exists that low-to-moderate alcohol consumption during pregnancy – less than one drink per day – is harmful to the fetus after the first three months of pregnancy, though they can't rule out risk completely" (Vancouver Sun 2007). Suggestions that some alcohol is acceptable were based on: 1) reports of new British guidelines, based on inconsistent evidence; 2) parenting books suggesting inconsistent evidence; 3) research suggesting a lack of evidence connecting light drinking or occasional binge drinking to harm; and 4) a study suggesting that a little alcohol when pregnant may prove beneficial. Various amounts were described as relatively safe, including: 1) low-to-moderate amounts; 2) light amounts; and 3) even occasional binge drinking.

Several articles outlined how Canadian experts found the British approach surprising, e.g., "[The doctor]… called the British move 'scary.' 'It's quite shocking for us to see it. It neglects, or just ignores, a huge body of evidence that does show mild drinking does cause issues'" (Edmonton Journal 2007). Of the articles suggesting the possibility of no harm after light or moderate drinking, only a few did not cite these British sources.

Drinking advice about risk factors for FASD development

Drinking advice focused on the safety of 1) different amounts of alcohol; 2) alcohol at different times; or 3) different kinds of alcohol. Fewer articles mentioned other factors besides alcohol involved in assessing risk. A few of these articles specified that not only alcoholics have children with FASD, e.g., "'The first myth is that FASD only occurs in alcohol-dependent women. All women are at risk.'" (Ottawa Citizen 2015).

Concerns about publicly communicating information about alcohol and pregnancy

Several articles outlined concerns about communication and public understanding of the risks of alcohol consumption during pregnancy. These included concerns about mixed messages leading to confusion (e.g., "Even her own doctor advised her to drink one or two gins to settle her stomach as a cure for morning sickness" (Vancouver Sun 2010)), and tension about what or how to tell women (e.g., "[The adoptive mother]… thinks it is 'mind-boggling irresponsible' for anyone to produce pregnancy materials that even hint at the possibility that drinking during pregnancy might be acceptable" (Toronto Star 2011)).

Discussion

Stigma surrounding FASD has been identified as an important issue for both individuals who are affected by FASD as well as women who give birth to children with FASD [12]. The implications of this stigma include negatively-affected life trajectories for individuals with FASD and fear of blame [30] and criminalization for women who drink while pregnant [31,32]. Our analysis of scientific and clinical print media content about FASD provides an overview of key science and health-oriented FASD themes to which the Canadian public could be exposed, and which could, in part, contribute to stereotyped understandings of FASD. We identified six themes related to scientific and clinical content (see Tables 1 and 2 respectively). Across these themes, we now explore three ethical concerns about this discourse that could perpetuate or produce stigma: 1) exaggeration about FASD rates in Indigenous communities, which could lead to harmful stereotyped beliefs about Indigenous peoples; 2) contradiction between articles about the effects of prenatal alcohol exposure, which might cause confusion about healthy choices during pregnancy; and 3) scientifically accurate information that neglects social context, which might unhelpfully inflame debates about sensitive issues (e.g., whether pregnant women should be punished for drinking alcohol). To discuss these issues, we take a two-pronged approach: 1) we compare information reported in the media with scientific literature, and 2) we discuss why we think each problem could perpetuate stigma about FASD, alcohol, and pregnancy.

Exaggeration: A potential source of harmful stereotypes about Indigenous peoples in Canada

Exaggeration beyond a given set of research findings can raise serious ethical concerns. For example, if hyperbolic and misleading claims are granted the veneer of scientific legitimacy by experts, previously untenable positions become more easily (if wrongly) defensible.[3] And while the goal of much research is to create generalizable knowledge, there exists a fine line between appropriately generalized claims and inappropriate exaggeration. When those claims begin to impact the social world, and beliefs about particular groups of people, there exists a danger of endorsing positions that turn generalizations into stereotypes. In this section, we explore current FASD prevalence data in Canada, and then discuss some of the reasons why Indigenous communities might have or be seen as having higher rates of FASD.

FASD prevalence in the general population: A case of limited data and extrapolation

Most conservative estimates suggest that FASD affects roughly 9 in 1000 Canadians [35]. However, given a lack of Canadian prevalence studies, this estimate has relied on American and European data from the 1980s and 1990s [1,2]. This means that we do not know what proportion of the Canadian population has FASD [1]. When journalists, the experts interviewed,

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[3] We want to emphasize that possible sources of exaggeration in media also include academic institutions and researchers, not only journalists and news editors. For example, a 2014 study by Sumner [33] concluded that "exaggeration in news is strongly associated with exaggeration in [institutional] press releases". Additionally, a 2015 study by Vinkers et al [34] found an increase in the use of superlatives (e.g., novel, innovative), and negative terms to a lesser extent, in scientific abstracts published from 1974-2014, concluding frankly that "scientists may assume that results and their implications have to be exaggerated and overstated in order to get published". Hype and exaggeration should be explored more thoroughly both within academic contexts as well as outside of them.

or editorial writers reported rates of roughly 1 in 100, and then translated that into "330,000 Canadians" or "11,000 Manitobans", they extrapolated based on external estimates combined with Canadian demographic data; these numbers do not necessarily represent diagnosed cases. That was rarely done transparently – although, as reported, a fair number of articles qualified these estimates with uncertainty, indicating a general acknowledgement of the limitations of current knowledge. Ultimately, readers could have assumed that these estimates were based on studies of the general population of Canada, when none exist.

Exaggerated FASD prevalence reported in Indigenous communities

The epidemiological studies that do exist in Canada have been done with subpopulations often deemed vulnerable, such as Indigenous peoples and criminal offenders [36], and sometimes at the intersection of these populations. Most of this work has been conducted in western Canadian provinces (i.e., Saskatchewan, Manitoba, and British Columbia), which aligns with our observation that most Canadian news coverage about FASD has emerged from those provinces. Despite variations in prevalence across studies, most of these subpopulation studies found rates far higher than the expected 1 in 100 (e.g., 1 in 10). In the case of Indigenous populations, these studies were conducted on specific, often remote reserves, with results that likely cannot be generalized to all Indigenous communities or groups; however, several news articles did not specify the region of study, simply reporting higher rates for Indigenous people overall – an exaggeration beyond existing findings. The results of these prior prevalence studies should not be taken as suggesting that all Indigenous groups are at higher risk for FASD, or that all Indigenous communities actually have higher rates.

What factors might contribute to exaggeration of FASD prevalence in Indigenous communities?

Concern about an exaggerated focus on Indigenous peoples reaches beyond the media. A disproportionate focus on FASD research in Indigenous groups in Canada – and a corresponding lack of research in the general population – may also contribute to exaggerated beliefs and assumptions about which groups are most affected by FASD. For example, one recent study noted that 51 of 52 reports on neurodevelopmental disabilities in Indigenous communities in Canada since 1981 focused exclusively on FASD (rather than other neurodevelopmental disabilities, like autism or cerebral palsy) [37]. Such biases in research could be fueled in part by common stereotypes attributed to Indigenous individuals (e.g., irresponsible drinking) [38], which may themselves be perpetuated in the kind of discourse we have analyzed here. This kind of reporting could lead to misconceptions about FASD as an Indigenous-only problem [37], which could lead to over-diagnosis or misdiagnosis of FASD in Indigenous peoples (see work by Tait for a more detailed exploration of this topic [39]). Beyond the FASD context, the needs of Indigenous peoples in Canada do not always match the goals of Canadian health research [40].

Articles addressing prevalence among Indigenous communities sometimes sought to mitigate the harm of problematic racial stereotypes; however, they did not analyze the situation in depth. Only one article in the sample featured an explanation for why some Indigenous people have FASD: “The grandmother is a survivor of the Indian residential school system who had her share of trouble with alcohol, a rough crowd and an abusive relationship as a young mother. ‘That’s how my children saw me… I passed it on’” (Winnipeg Free Press 2011). It is important to keep in mind that Canada’s racist residential school system kidnapped Indigenous children from their families, forcing them to assimilate – stripping them of their languages and cultural practices (sometimes referred to as ‘cultural genocide’) [41]. Many suffered from abuse, and many other children died. Residential schools are only one recent example of forced assimilation in Canada, the effects of which are still felt today in some Indigenous communities where high suicide rates, increased alcohol consumption, disproportionate prison representation, and poor health outcomes can be prevalent [42].

Only a few articles implied a connection between a history of colonialism, any potential alcoholism, and FASD, presenting the information in a list of facts that allowed readers to draw their own conclusions: “98% of adults are alcoholics. That includes 99% of the community’s residential school survivors” (National Post 2007). Readers here are given little context as to why some Indigenous groups might drink more. The public could therefore interpret this in a way that conforms to pernicious, racist stereotypes about Indigenous peoples. This situation stands in stark contrast to the recent Calls to Action of the Truth and Reconciliation Commission of Canada regarding “media and reconciliation”, calling for more comprehensive coverage of Indigenous populations with a specific focus on and careful attention to the history and legacy of residential schools in Canada (Call to Action 84, point iii) [41].[4]

Contradictions between articles about the effects of prenatal alcohol exposure: A potential source of confusion

Identifying causal links between different amounts of alcohol, prenatal alcohol exposure, and developmental outcomes remains difficult given a number of confounding variables (e.g., genetics, metabolism, socioeconomic status). This complexity can pose a major challenge to communicating clear public health information. Consequently, many health organizations, including the Public Health Agency of Canada [43], favour the message that no amount of alcohol is safe to drink at any time during a pregnancy. When this topic was raised in our media

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[4] We should note that Calls to Action 33 and 34 explicitly address the issue of FASD in Indigenous communities [41]. Action 33 calls for FASD prevention programs developed collaboratively and “delivered in a culturally appropriate manner”. Action 34 calls for criminal justice reforms for offenders with FASD. The latter Call to Action reflects concerns seen in our data, in discussions about Indigenous communities, FASD, and criminal behaviour. Please see our other manuscript based on this dataset for further discussion of the connection between crime and FASD [26].

sample, the ‘no alcohol’ message was dominant; however, contradictions between articles appeared as we analyzed the whole sample. For example, as reported, light drinking was presented as harming, not harming, and even helping child development – with different definitions of light drinking presented. These contradictions could lead to public confusion about whether or not drinking small amounts of alcohol is harmful when pregnant, despite attempts at clear public health messaging.

Contradiction about how much alcohol can harm a fetus in the academic literature

High levels of prenatal alcohol exposure, linked to heavy regular drinking or binging, can have a negative impact on neurodevelopment [44]. This amount of alcohol does not have an impact in each and every case, but increased prenatal alcohol exposure is generally associated with increased risk of FASD [45]. In contrast, debate continues over the effects of light – and to a lesser extent moderate – prenatal alcohol exposure [46]. Depending on the outcomes measured (e.g., IQ, head size), the definition of light drinking, the variables controlled, or the population studied, light drinking has been found to be both harmful [47] and not harmful [48]. The overall evidence seems to be weighted toward ‘not harmful’, but uncertainties that persist in the academic literature appear to extend into the public sphere, potentially contributing to conflicting medical advice about alcohol use – i.e., some evidence suggests that medical professionals may not broach the topic of alcohol with their pregnant patients beyond routine screening, or else might provide unspecific advice about medical risks, partly to ease patient anxieties [49].

When can clear and certain messaging backfire – and what messages might work better?

Although clear messaging and discourse that fosters negative public attitudes toward drinking while pregnant can be useful from a public health perspective (i.e., discouraging unhealthy behaviour at the population level), it could also unhelpfully stigmatise individual women who do drink [12,50]. The clarity and certainty of abstinence messaging could, in some cases, have an effect opposite to the one intended, rigidifying public opinion against women most in need of support, and driving those women ‘underground’ [31]. Concerns about drinking have even begun to expand beyond the category of pregnancy, as medical advice shifts toward the implication that fertile women live in a constant state of pre-pregnancy. For example, recent CDC advice to doctors suggested they should “recommend birth control to women who are having sex (if appropriate), not planning to get pregnant, and drinking alcohol” [51]. In this way, responsibility and blame for FASD largely lands on women alone [32,52]. This concern is highlighted by the fact that barely any of the articles in our sample mentioned the contribution of family, partners, or social circles to an alcohol-free pregnancy. If both alcohol use and parenthood were understood in more community-oriented terms, rather than as the individual actions and responsibilities of solitary women, prevention methods and messages could shift toward social support, rather than blame and shame.[5]

However, even with less judgmental and more community-oriented approaches, the problem of uncertainty remains. A clear tension exists between 1) public health and medical guidelines requiring clear and actionable messages; 2) ensuring that marginalized women feel supported throughout their pregnancies; and 3) the importance of communicating the truth about research findings – even if that truth involves complexities. If media were to communicate only the clear but rigid message of abstinence in all cases, then the previously outlined issues of stigmatisation could arise, along with questions about paternalistic approaches to women’s healthcare [53]; however, if contradictions are reported without care, some worry that this could

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[5] For a more detailed discussion of gendered concerns around how and why women can sometimes be framed as the sole actor responsible for the wellbeing of their children – and where blame and shame can become criminalization and forced intervention – see [26].

provide women with a “license to drink” [50]. In our sample, contradiction more often appeared without comment between, rather than within, articles. To that end, a kind of compromise could be reached, whereby news articles could try to place such claims in the context of the literature – emphasizing both the public health messages and the current state of research together.

Accurate science and health information, without context: A source of stigma?

Even if science and health communication were completely accurate, the social context of the research in question may nevertheless be considerably important. Presenting only the ‘facts of the matter’ without an understanding of this context could unnecessarily inflame tensions, and further stigmatise affected groups. For example, presenting Indigenous prevalence data without qualification could exacerbate racial tensions in Canada, which, again, goes against the spirit of the Truth and Reconciliation Commission’s Calls to Action [41]. In this section, we examine the importance of social context for better understanding different dimensions of FASD.

Social context and women who drink while pregnant

While it is technically true that “FASD… is 100 per cent preventable” (Calgary Herald, 2005) – in the sense that if all pregnant women abstained from alcohol, no child would ever be born with FASD – women typically have reasons for drinking that are not so easily addressed. For example, some struggle with addiction, or use alcohol as a coping mechanism, while others are entirely unaware of their pregnancy [54]. Explaining the social context of alcohol use is therefore both constitutive of a truly scientific understanding of FASD and necessary so as to avoid simplistic public narratives about alcohol and pregnancy.

Failing to critically attend to reasons for drinking ultimately feeds into narratives that emphasize maternal blame and shame, which could have the unintended effect of making it more difficult for women to reach out for help [31] or can lead to punitive rather than rehabilitative or supportive interventions. In our sample, although a few articles explored how women might need a non-judgmental environment in which to seek assistance, most described FASD as "the leading cause of" preventable disability, some even going so far as to describe FASD as "easily" or "highly" preventable. Calls for public acknowledgement of more critical and nuanced messaging were few; most media discourse concluded that abstinence-only messaging remains both necessary and appropriate. Concerns about stigmatisation could be a strong reason to re-examine current prevention messaging and awareness campaigns, to better understand unwanted or unintended side-effects of FASD discourse. If FASD is seen as easily preventable, then women who fail in the task of prevention can be more easily marginalized.

Social context and people with FASD

In the case of people with FASD, discourse was often negative, even hopeless – e.g., as reported, people with FASD were sometimes described as a financial burden on society. People with FASD were commonly described as victims (e.g., of 'irresponsible mothers', of crime) [26], and long lists of symptoms categorized, organized, and explained differently in each case served as unqualified examples of their suffering. And while we should never dismiss the self-reported struggles and pain of people with FASD, focusing so strongly on weaknesses and challenges, rather than on any strengths and successes, painted their lives rather bleakly. Ultimately, framing FASD as hopeless and desirably preventable might also stigmatise people currently living with the diagnosis. Hopelessness could contribute to the sense that nothing can be done (leading to limited or poor interventions and support), while prevention framing raises concerns similar to the 'expressivist objection': that "prenatal diagnosis expresses a discriminatory or negative attitude towards people with disability" [55]. Managing the tension between respecting individuals who have already been born with FASD, and the desire to prevent individuals from being born with it in the future, should be carefully considered. Within prevention efforts, how scientists, healthcare professionals, journalists, and members of the public choose to talk about FASD as unwanted could have a major impact on the lives of people with FASD. The framing of health and science information matters; it is important to acknowledge the social context in which research and medicine are embedded.

Limitations

This study has several limitations, which we have reported in full elsewhere, some of which is reprinted here or specific to this text [26]. First, we only searched for keywords in article headlines and lead paragraphs to ensure that they were central to the story being told. Second, our sample focused on stories from the most-distributed newspapers in Canada, which meant only those from Canada's larger cities and provinces.

Third, there were several limitations tied to the availability of sources. For example, Factiva only included major French newspapers in Canada as of 2011. While we do not know if these sources discussed FASD before 2011, no articles were found from 2011-2015. This could be due to differences in knowledge across Canada [6-8], differences in attitudes about drinking [56], or our choice of keywords. Three sources also have minor gaps in database coverage (i.e., the Toronto Star, the Edmonton Journal, and the Vancouver Province). In addition, as of 2010, six of ten newspapers were owned by a single corporation (Postmedia), which might have had an influence on the kind of coverage we analyzed.

Fourth, most of the discarded codes that failed the reliability test related to key issues in the study of and care for people with FASD – specifically, prevention and FASD's cause. In part, the theme of prevention overlaps with our analysis of the theme of treatment, since care for at-risk or alcoholic mothers often serves as FASD prevention. In the case of FASD's cause, while we lack a detailed analysis, several other codes clarified relevant variables connected to risks for having a child with FASD, so the missing analysis has been partly addressed elsewhere. Finally, we did not undertake separate analyses on the impact of events that could have led to increased or decreased media coverage (e.g., the CIHR award for Winnipeg Free Press coverage of FASD).

Conclusion

Our analysis of science and health content in Canadian newspaper articles discussing FASD identified six key themes: 1) prevalence of FASD and of women's alcohol consumption; 2) research related to FASD; 3) diagnosis of FASD; 4) treatment of FASD and maternal substance abuse; 5) primary disabilities associated with FASD; and 6) effects of alcohol exposure during pregnancy. These results were discussed in light of three major concerns: 1) exaggeration about FASD rates in Indigenous communities, which could perpetuate harmful stereotypes and myths about Indigenous peoples (e.g., 'the drunk Indian'); 2) contradiction between articles about the effects of prenatal alcohol exposure, which could create public confusion; and 3) scientifically accurate (but incomplete) information that neglects the social context of alcohol use/abuse by women, which could unnecessarily inflame social tensions and attitudes toward marginalized groups (e.g., leading to calls for pregnant women who drink to be 'locked up'). Looking forward, ethical considerations surrounding communication about FASD, alcohol, and pregnancy in the public sphere should be further explored, to better understand, recommend, and test more appropriate messaging, especially in the context of stigmatisation, scientific uncertainty, and stereotyping about Indigenous peoples, women who consume alcohol during pregnancy, and people with disabilities. We hope that such work and coverage would help improve public attitudes, social accommodations, and opportunities or programs for support.

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Concluding remarks for chapter 3: Science and health communication

In this paper, we explored several challenges and pitfalls associated with science and health communication: exaggeration, contradiction, and missing social context. While concerns about issues like exaggeration call rather straightforwardly for more accuracy in reporting, these issues also speak to broader challenges of the science and health news ecosystem. For example, news reports (as scientific research does) often focus on novel findings [146] and reflect scientific uncertainty [88], making it difficult to place recent work in the context of an existing body of literature and to find alignment between health messaging and news information. Considering declining revenues in print news [147] and that few reporters focus exclusively on science and health [148],[12] practices antithetical to good reporting have emerged; among them, the issue of churnalism – the uncritical recycling of press releases, wire reports, and social media as news content [149]. In the context of science and health news, this relates in part to exaggeration in university press releases [96].

Similarly, as discussed in Chapter 2, audiences receive, understand, and make use of information and discourse based on more than accuracy and context; audiences filter information through biases, ideologies, trusted sources, political alignment, religiosity, and other lenses [94]. When a socially contentious issue is raised in discourse with potential political implications (i.e., systemic racism affecting Indigenous peoples in Canada, policies on substance use – especially during pregnancy – and expectations about motherhood), more accurate and contextualized information may not shift those beliefs meaningfully alone. This, in part, contributed to the decision to ask FASD stakeholders for reactions and suggestions on how to fundamentally shift or improve discourse about FASD, alcohol, and pregnancy in Canada (please see Chapters 5-7).

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[12] Although, in this ongoing pandemic, we have seen enormous efforts to communicate a unique health crisis.

CHAPTER FOUR – STEREOTYPES AND STIGMA ASSOCIATED WITH THE STORIES WE TELL ABOUT FASD, ALCOHOL, AND PREGNANCY

Manuscript II: Stereotyping and stigmatising disability: A content analysis of Canadian print news media about fetal alcohol spectrum disorder

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Abstract

People with fetal alcohol spectrum disorder (FASD), a complex and controversial neurodevelopmental disability caused by alcohol exposure in the womb, report experiences of stigma in different parts of their lives. The media, sometimes central to how a public understands and constructs marginalized identities, have a notable history of poorly representing people with disabilities like FASD (including in Canada), which could increase their stigmatisation. Additionally, given its cause, women who drink while pregnant can also face stigmatisation – with some public discourses evoking narratives that promote blame and shame. To gain insight into the kinds of information presented to Canadians about FASD, alcohol, and pregnancy, we conducted a media content analysis of 286 articles retrieved from ten of the top Canadian newspapers (2002-2015). In this article, we report key themes we identified, most common being 'crime associated with FASD'. We explore connections between this coverage, common disability stereotypes (i.e., criminal behaviour and 'the villain'), FASD stigma, and expectations of motherhood.

Keywords: stigma; stereotypes; disability; fetal alcohol spectrum disorder; FASD; alcohol and pregnancy; media content analysis; motherhood

Introduction

Stigmatisation, a process of negative stereotyping that can cause discrimination, remains a tremendous social challenge and a barrier to the wellbeing of marginalized populations. Link and Phelan (2001) describe stigmatisation as a process involving the "co-occurrence" of several key components: group differences deemed salient by a given society become fodder for stereotyping, othering, and discrimination in a context where various forms of power align against a particular group. Public attitudes toward – and narratives about – a group can impact how societies understand, perceive, and support them. In this paper, we focus on how common media stereotypes could contribute to the stigmatisation of two such groups: 1) people with a neurodevelopmental disability called fetal alcohol spectrum disorder (FASD); and 2) women who drink while pregnant. We analyzed Canadian print news media about FASD and drinking during pregnancy to better understand the information readily accessible to many Canadians.

What does a diagnosis of FASD entail, medically and socially?

FASD, a complex and controversial diagnosis, results from fetal exposure to alcohol in utero (Cook et al. 2016; Chudley et al. 2005). When the diagnosis first emerged, it was initially attributed to children of "chronic alcoholic women" (Jones et al. 1973); however, the diagnosis soon expanded to encompass a wider spectrum of potentially affected individuals (Armstrong 1998; Koren et al. 2003). FASD presents heterogeneously; it can present with or without facial features, and may affect executive function, behaviour, and cognition, among other "brain domains" (e.g., motor function, language) (Cook et al. 2016; Chudley et al. 2005). These differences are sometimes referred to as "primary disabilities" in the medical literature (Koren et al. 2003), meaning "those that reflect the [central nervous system] dysfunctions inherent to the… diagnosis" (Streissguth et al. 1996). Recent Canadian diagnostic guidelines categorize FASD as:

1) FASD with sentinel facial features; 2) FASD without sentinel facial features; and 3) an at-risk category that does not yet indicate diagnosis (Cook et al. 2016). To be diagnosed, an individual must present with deficits in three of ten key “brain domains” and should typically have confirmed prenatal alcohol exposure. Ultimately, FASD is a difficult-to-assess diagnosis that requires diagnostic evaluation by a large multidisciplinary team – including physicians, speech language pathologists, social workers, and others.

The “primary disabilities” of FASD can be distinguished from more complex “secondary disabilities”,[1] which include social sequelae and issues like homelessness, criminal behaviour, and substance abuse (Streissguth et al. 1996). While primary disabilities have been described as arising directly from neurological damage caused by alcohol, secondary disabilities relate to how people with FASD integrate into society as they age because of their primary disabilities.[2]

Importantly, people with FASD have reported facing problems such as social exclusion, poor support systems, and employment discrimination (Salmon and Buetow 2012; Stade et al. 2011), which constitute potential consequences of the stigmatisation process described by Link and Phelan (2001). Additionally, women who consume alcohol during pregnancy can face stigmatisation given the connection between alcohol and an FASD diagnosis (Eggertson 2013; Salmon 2008; Abadir and Ickowicz 2016). For example, public discourse and health messages that emphasize blame, shame, and a mother’s individual responsibility can feed into stereotyped portrayals of women who drink while pregnant as unfit, irresponsible, and even criminally

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[1] The use of the term “disability” to refer to both biological impairments and their interactions with the social environment does not align well with disability studies conceptions of disability. For a detailed exploration of distinctions and relationships between ideas like disability and impairment, the latter of which the notion of “primary disabilities” likely more accurately reflects, see Mike Oliver’s chapter on the topic (1996).

[2] We can see in these descriptions a model of disability oriented more toward the individual or medical – one that emphasizes impairment as the primary (though not necessarily singular) cause of disability. There are also other potentially relevant factors, like childhood trauma or bad experiences in group home environments.

negligent or evil mothers (Connolly-Ahern and Broadway 2008; Lowe, Lee, and Yardley 2010).

This study builds on previous media studies about FASD, alcohol, and pregnancy conducted in the UK (Lowe, Lee, and Yardley 2010), the US (Connolly-Ahern and Broadway 2008; Golden 2000), and Australia (Eguiagaray, Scholz, and Giorgi 2016; McCallum and Holland 2017). Each of these studies reported tensions around the construction of different and sometimes conflicting FASD stakeholder identities (e.g., people with FASD as victims of bad blameworthy birth mothers). Half of the studies had an explicit focus on alcohol and pregnancy over FASD itself. In principle, the Canadian context ought to bear similarities with the contexts previously studied given their related histories. For example, Australia and Canada have similar relationships to colonization and their treatment of Indigenous peoples, and one Australian study reported on Indigenous peoples in FASD coverage (Holland, McCallum, and Blood 2015). However, Canadian coverage merits its own investigation, given its potential impact on the construction and portrayal of FASD, and its interface with Canadian public health.

Disability stereotypes and stigmatisation in the media

The media, whether in the form of news, advertising, or entertainment, have a long history of poorly representing people with disabilities (Barnes 1992; Day 2000; Devotta, Wilton, and Yiannakoulias 2013). Scholars have pointed to stereotyped portrayals of disability as potential sources of negative public attitudes, prejudice, and discrimination (Barnes 1992; Day 2000). In both fiction and news stories, people with disabilities can serve as one-dimensional narrative devices or objects used to evoke strong emotional responses in able-bodied audiences, rather than as complex and fully fleshed out individuals with their own experiences.

People with disabilities are often framed as victims or objects of pity (e.g., Tiny Tim in Charles Dickens' *A Christmas Carol*: a sick child with a crutch), as burdens (e.g., *Rain Man*: an autistic man whose brother initially sees him as a burden), as super-heroic (e.g., *Daredevil*: a blind superhero with heightened senses), or as villainous (e.g., *Richard the III* in Shakespeare's eponymous play has a curved spine, Joker in *Batman*: mentally ill and often confined to an asylum). These ideas do not just exist in fiction; many of these same stereotypes have been identified in Canadian newspapers (Haller et al. 2012), among other news media (Barnes 1992). Given the heterogeneity of disabilities, these stereotypes "paint a rather distorted picture that is at odds with the way disabled people see themselves" (Day 2000). Ultimately, these stereotypes provoke concerns about cultural representations of individuals with disabilities and the impact of these stereotypes in generating and perpetuating a process of stigmatisation.

Like any complex or poorly understood disability, the FASD diagnosis itself could be a catalyst for stigmatisation; the group difference deemed salient is a set of symptoms attached to a diagnostic label, to which stereotypes could additionally be attached. However, unlike most other diagnoses, the impact of the FASD label spreads beyond the individual themselves, since a diagnosis of FASD may also tell us something about a biological mother's behaviour.

Motherhood stereotypes and expectations in the context of alcohol consumption

Women regularly experience double standards, stereotypes, and gendered expectations about what it means to be a good person, woman, or mother (Armstrong 2003). For example, Ganong and Coleman (1995) describe the "American myth of motherhood", which suggests that mothers are either "all good" (i.e., "perfectly loving, kind, patient, and giving") or "all bad" (i.e., "rejecting, cold, and controlling"). They argue that this myth holds mothers responsible for their children's wellbeing, while the role played by fathers is largely ignored. Essentially, in focusing on the behaviour of individual mothers, societies might then ignore social structures and social pressures that also contribute to these behaviours. Women who consume alcohol while pregnant could represent a strong case of the perceived “all bad” mother.

Exploring the history of Western attitudes toward women who consume alcohol, Carter (1997) explains that, in the United States in the late 1800s, women “who drank publicly or became drunk were considered sexually indiscreet and *irresponsible mothers*” [emphasis ours]. Even in the 1990s, women were still reduced to roles related to their sexual availability, or else their ability to reproduce and care for children (Carter 1997). Indeed, Armstrong (1998), in an article exploring the origin of the FASD diagnosis, points to major social changes during the 1960s-70s that generated “social distress about women’s propensity to act in ways that were independent of and perhaps in opposition to the maternal role as socially constructed”. She quotes Daniels (1993), who argues that “some women were not just [viewed as] bad mothers, but as ‘anti-mothers’ who violated their most fundamental natural instincts and who threatened to destroy the institutions of motherhood altogether”. Such historical context and shifting social roles (at least in the United States) reflected a growing “moral panic” surrounding alcohol use and pregnancy, which likely had an effect on North American reactions to the creation of the diagnosis of FASD (Armstrong and Abel 2000).

At the most basic level, stereotypes attached to the labels of ‘good’ or ‘bad’ mother could have a significant impact on public attitudes toward pregnant women. Some recent evidence even suggests that birth mothers of children with FASD are perceived as more blameworthy than other ‘bad’ women (e.g., incarcerated women) (Corrigan et al. 2017)[3]. In the end, the complex relationship between attitudes toward women, mothers, and children with disabilities leads to many possible sources of stigmatization in FASD (Bell et al. 2015).

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[3] However, this study presents a few methodological limitations. The categories of women (i.e., with mental illness, with substance abuse issues, who have been jailed for minor offences, and birth mothers of people with FASD) can overlap. In addition, the description of birth mothers seems more negative than descriptions of the other groups.

In this paper, we explore Canadian print news media coverage of FASD. We focus on the portrayal of two key stakeholder groups: 1) people with FASD; and 2) women who drink while pregnant, with the aim of deconstructing stereotypes. We find that both individuals with FASD and mothers giving birth to children with FASD have been, at times, stigmatized as bad or as villains – consistent with previous literature (Connolly-Ahern and Broadway 2008; Dej 2011). However, Canadian print news media also contained some notable pushback against these stereotypes. We critically reflect on the connections between this coverage and problematic ways of constructing and portraying the identities of both people with disabilities and mothers.

Methods

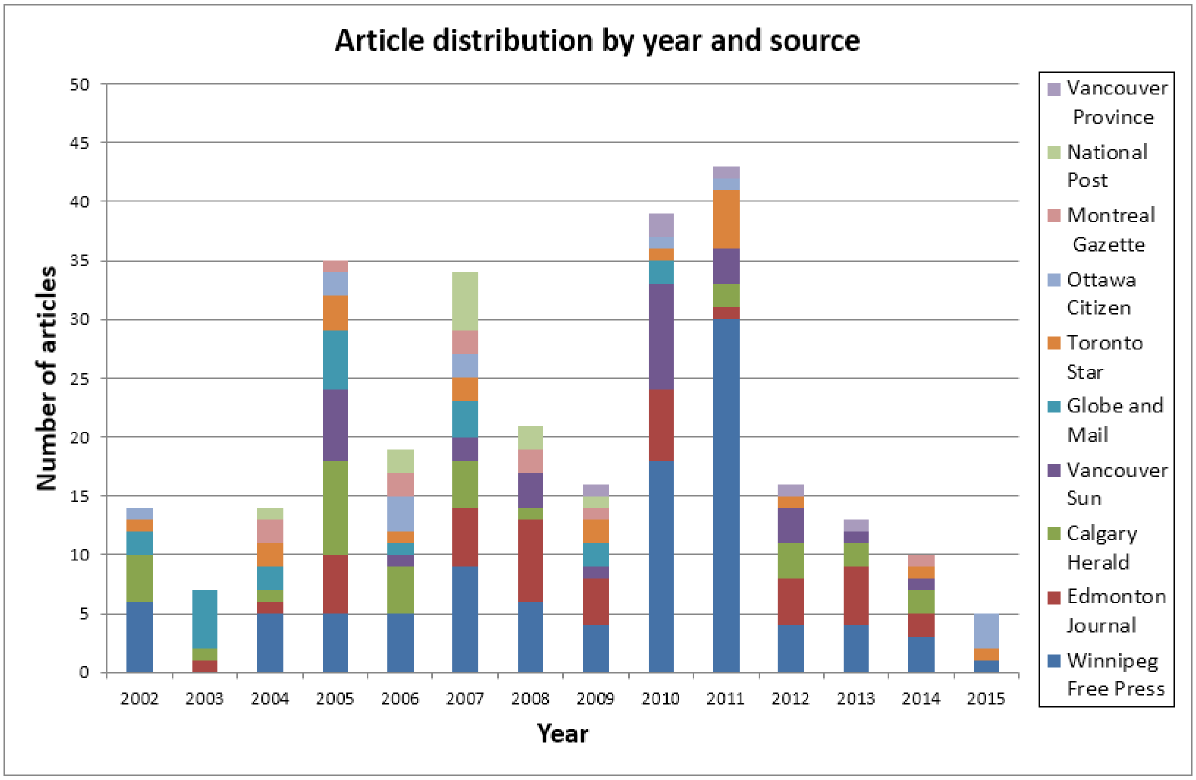
In this study, we employed media content analysis (Macnamara 2005), similar to several previous studies conducted at our research unit (e.g., Racine, Bar-Ilan, and Illes 2006).

Sample

Using the Factiva news database, we searched for English and French print news articles published in Canada between January 1st 2002 and October 31st 2015, capturing media coverage from roughly the past fifteen years. We searched for the following keywords in headlines and lead paragraphs: “("fetal alcohol spectrum disorder" OR "FASD" OR "fetal alcohol syndrome" OR ("alcohol" AND "pregnancy") OR "ensemble des troubles causés par l’alcoolisation foetale" OR "ETCAF" OR "syndrome d’alcoolisation foetale" OR (“grossesse” AND “alcool”))”.

We restricted our search to ten of the most-distributed Canadian print news sources (Newspapers Canada 2009), all of which are available electronically: *The Toronto Star (20), The Globe and Mail (22), The Montreal Gazette (11), The Vancouver Sun (30), The Vancouver Province (6), The National Post (11), The Winnipeg Free Press (100), The Calgary Herald (32),* *The Ottawa Citizen (13),* and *The Edmonton Journal (41)*[4]. We excluded *Le Journal de Montréal, La Presse, Le Journal de Québec,* and *The Toronto Sun* because Factiva only began archiving these sources in 2011. See Figure 1 for more information about the distribution of the sample by year and by source.

Figure 1: *Distribution of articles across the sample, sorted by year and by source. The colour legend for sources and the stacked bars themselves are organized in ascending order, from the Winnipeg Free Press at the bottom (n=100) to the Vancouver Province on the top (n=6).*



Of the original 398 articles, we retained 286 after excluding: 1) articles we deemed to be irrelevant; 2) duplicates from the same source; and 3) short news briefs, which included synopses of several articles at once (not all FASD-related), summaries of articles already in the sample,

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[4] More than one third of this sample (100/286 articles) came from The Winnipeg Free Press, which won a 2010 CIHR grant to cover FASD and its "causes, social costs, treatments, and prevention" [quote in sample]. Throughout 2010 and 2011, they published 18 and 30 articles respectively, accounting for just under 17% of the total sample (48/286 articles). Even without the CIHR award, they would still have had the most FASD coverage (52 articles, compared to 41 from the Edmonton Journal and 32 from the Calgary Herald). Of the rest of the articles, more than a third came from the other Western provinces (British Columbia and Alberta – no newspaper from Saskatchewan was included). In total, almost three quarters of the sample comes from these three Western provinces, with only 27% (77/286 articles) coming from Ontario, English Quebec news, or national papers like The Globe & Mail.

and articles with too little content. Thirty-eight of the 286 retained articles were duplicates from different sources, which we included in our analysis to capture far-reaching messages.

Coding process

The initial coding guide was inductively developed by three coders using 25 randomly-selected articles from 2002-2011. We used NVivo (QSR International, Version 9.2.81.0) for coding and data analysis. Coder 1 then applied this guide to the remainder of the overall sample using a rich coding strategy (i.e., overlapping, non-mutually-exclusive codes). Coder 2 then conducted blind coding on another random sample of 25 articles to assess inter-coder reliability. Reliability was calculated in percent agreement for all main codes and sub-codes. Six codes and five sub-codes had percent agreement below 0.75 and were eliminated from the data. For quantitative analyses, we used individual articles as the sampling unit. After updating the sample to include articles published between 2012-2015, a fourth coder undertook a more detailed qualitative unpacking of the data, which led to further refinement of the coding guide. We then had a fifth coder conduct another round of blind coding on another random sample of 25 articles, to assess inter-coder reliability of the reorganized codes and sub-codes.

Coding Guide

We coded 286 articles for coverage of three broad categories: 1) scientific content; 2) clinical content; and 3) social content. This article reports on the eight codes (and eleven sub-codes) in the social content category (See Table 1). The scientific and clinical content will be reported elsewhere (Aspler et al., 2019). Social content reflects discussions about the lives and needs of people with FASD and women who drink while pregnant. As the broadest category, categories included issues like crime, stigma and labelling, funding, and more.

Results

We identified eight major themes, or codes, (See Table 1) broken down across eleven sub-codes, with the most frequent being crime associated with FASD (37%, n=106). Table 1 describes the coding structure in detail and explains the scope of each code and sub-code with examples. In the text that follows, we provide a detailed overview of some of the richer and more complex themes. Illustrative examples are used to exemplify important qualitative aspects of the content, with key quotes provided in-text.

Table 1 – Results: Coding Structure, Percentage of Sample, and Illustrative Examples

Code	Sub-code	Scope	% of sample # of articles	**Examples**
Crime associated with FASD		Article reports on crime associated with FASD	37%, n=106	
	Perpetrator of crime	Article reports on people with FASD as perpetrators of crimes; not always specific cases	29%, n=83	"A 14-year-old resident of a facility for youngsters diagnosed with FAS has been charged with first-degree murder in the case" (Calgary Herald 2002).
	Victim of crime	Article reports on people with FASD as victims of crime; not always specific cases	8%, n=23	"Two teenage boys suffering from [FASD] had been confined to makeshift cages fashioned from cribs and were beaten regularly..." (Toronto Star 2004).
More support needed for FASD stakeholders		Article reports on the need for any kind of increased FASD support. Includes requests for specific programs and services, as well as broad calls for general support and funding.	29%, n=82	"Doctors dealing with the disorder say there is a dire need for more diagnostic services" (Toronto Star 2009).
Awareness of FASD		Article reports on efforts to raise awareness about FASD and the impact of drinking while pregnant, and the need for greater awareness. Includes reports about current public awareness.	28%, n=81	"People from Norway House Cree Nation will walk and run to Winnipeg... to draw attention to FASD" (Winnipeg Free Press 2010).

Family composition of people with FASD		Article reports on the family makeup of individuals with FASD.	27%, n=73	
	Adoptive families	Article reports on people with FASD who have been or might be adopted. Includes stories about children diagnosed and sometimes given up or placed in care long after adoption. Also includes calls for more support for adoptive parents.	13%, n=38	“The Jaffrays adopted [their children] when both were newborns with little inkling that they might suffer from FAS” (Toronto Star 2002).
	Foster Families	Article reports on children with FASD who live in or who may end up in the foster care system. Also includes concerns about foster families rejecting children with FASD, and how likely they are to remain in foster care compared to other populations.	5%, n=15	“He was diagnosed with fetal alcohol syndrome when he was two. In the past 15 year he’s lived in seven different foster and group homes” (Winnipeg Free Press 2006).
	Parents who have FASD	Article reports on people with FASD who have or who could have children; not always in reference to specific individuals.	3%, n=10	“Most will say it’s a cycle, and that a woman with many fetal alcohol-affected kids was born to a woman who drank while pregnant, too” (Winnipeg Free Press).
Funding for FASD		Article reports funding for research, prevention, diagnosis, treatment, or other services. Includes calls for increased or better-directed funding, and complaints about current funding issues. Note that most referred to government funding in the western Canadian provinces of Manitoba, Vancouver, and Alberta.	25%, n=72	“Alberta’s decision to create a more co-ordinated system for dealing with FASD, and to hike spending to $10 million a year -- a $4-million increase -- is significant…” (Calgary Herald 2007).
FASD and Indigenous populations in Canada		Article reports on Indigenous peoples and communities in Canada in the FASD context	22%, n=62	“About 48 per cent of aboriginal people strongly support a school screening program. That could be because FASD is widely seen as an aboriginal issue, even though it affects all groups” (Winnipeg Free Press 2011).

Secondary disabilities associated with FASD		Article reports on secondary disabilities associated with FASD, sometimes explicitly using the term.	21%, n=60	"… people with FAS face daunting odds of dropping out of school, getting fired from jobs, becoming teenage parents, dabbling in drugs, tangling with the police and drifting in and out of homelessness" (Globe and Mail 2003).
	Substance abuse	Article reports on substance abuse or potential substance abuse by people with FASD	7%, n=20	
	Employment	Article reports unemployment or issues keeping a job for people with FASD	5%, n=14	
	Housing	Article reports homelessness or issues with independent living for people with FASD	4%, n=11	
	Inappropriate sexual behaviour	Article reports inappropriate sexual behaviour as a secondary disability of FASD. Excludes specific criminal cases featuring either a perpetrator or victim with FASD	1%, n=4	
Impact of the social world on FASD		Article explores certain social factors that could impact or that could be impacted by FASD	21%, n=59	
	Stigma and Labelling	Article reports on the impact or the sources of stigma and labels associated with FASD on both people with FASD and women who drink while pregnant.	12%, n=35	"They almost never show clear signs of the facial dysmorphia that comes with FAS and spend their lives stigmatized for their unrecognized permanent brain damage" (Toronto Star 2005).
	Socioeconomic status	Article reports on socioeconomic status in the context of FASD	9%, n=26	"Its victims are often the children of poor mothers who suffer substance abuse and addiction" (Globe and Mail 2007).

Crime associated with FASD

Perpetrator of crime – Criminal justice and culpability

Many articles coded here included explicit examples of crimes committed or allegedly committed by people with or suspected of having FASD (e.g., theft, arson, murder). Here, the media broadly framed people with FASD as either more likely to commit crimes than the average person or as comprising a disproportionate fraction of the Canadian inmate population. A few articles also discussed how the criminal justice system sometimes fails or does not appropriately accommodate people with FASD, as suggested in a 2012 article from the Edmonton Post: "'…treatment availabilities while one is incarcerated, especially if overcrowding is an issue… are very, very minimal. The jails then become a bit of a dumping ground for problems in society that we haven't been able to appropriately deal with'".

Many articles also raised questions about the ways certain deficits associated with FASD could impact an individual's moral or criminal culpability. For example, some suggested that these alleged perpetrators lacked insight into the consequences of their actions, as in a Winnipeg Free Press article from 2010: "…an older FASD teenager who appears normal often considers consequence -- while joining a gang or stealing a car -- in much the same way as a four-year-old". In the case of minor offences, a lack of insight into consequences could reportedly lead to further trouble for these individuals (e.g., "…[people with FASD are susceptible to] charges, such as failure to appear, breach of probation or failure to comply with bail conditions… because of their struggles to stay organized and understand consequences" (Edmonton Journal 2013)). Some articles also suggested that consequence-based punishment like incarceration may not be effective for people with FASD if they have a deficit in understanding consequences.

In contrast, other articles focused on an inability to assess the rightness or wrongness of their actions, as in this 2006 Winnipeg Free Press article: "and justice officials are trying to find a way to punish youths who often have no concept of right and wrong". A final small set of articles suggested that, regardless of the ability to evaluate the morality of consequences or actions, the issue has to do with impulse control and intention: "'He knows it's wrong, but he doesn't have the ability to self-regulate'" (Winnipeg Free Press 2011) or "'He knew that it was wrong… but I hesitate to say that he knew that he wanted her dead'" (The Globe and Mail 2005).

Finally, these discussions about culpability explored the importance of considering a diagnosis of FASD as a mitigating factor during sentencing. Notably, some of these articles included perspectives that acknowledged potential deficits in understanding, but still privileged public safety over the needs of the accused (e.g., "What does society do with an habitual arsonist or a chronic car thief except jail them?" (Winnipeg Free Press 2010)).

Victim of crime

Most of these articles focused on stories of people with FASD as victims of crimes (e.g., of murder, of abuse), mostly about men or boys, although the few examples of female victims were typically about sexual assault or exploitation. A few articles discussed broader concerns about victimization, such as increased likelihood of people with FASD being victims of crime (e.g., "A famous research study on kids with FASD in the U.S. Pacific Northwest found 72 per cent of FASD kids studied had been victims of abuse" (Winnipeg Free Press 2011)), or problems faced in the criminal justice system, as in this Winnipeg Free Press article: "The prosecutor was warned the child [with FASD] would make a horrible witness [testifying against his father in a sexual abuse case] and couldn't understand abstract questions… It resulted in the judge accusing the boy of lying and the father being released" (2011).

Family composition of people with FASD

Parent with FASD – Fathers and mothers with FASD portrayed differently

Some articles in our sample focused on the whole lifecycle, including what happened when individuals with FASD had children of their own. Many articles discussed how these children were cared for by other family members (e.g., grandparents) or were placed in foster or adoptive care. These stories typically discussed mothers with FASD, but a few focused on fathers with FASD. The articles about mothers included a mix of A) successful parenting stories: "[She] has a loving husband, three beautiful children and… a fetal alcohol spectrum disorder that affects her memory and her brain's ability to get organized…" (Winnipeg Free Press 2011); and B) less successful stories, as in this 2012 Edmonton Journal article: "'[She] is a very nice girl and is funny and can be very sweet at times'… But she is not fit to raise a child. The government agreed and the baby is in foster care". All of the articles about fathers were framed positively and focused on overcoming hardship to live stable lives: "For more than a decade, [he] has been accompanied 12 hours a day, seven days a week, by a support worker from the Mennonite Central Committee. He now takes his girlfriend and 10-month-old daughter to work with him to keep him motivated" (Winnipeg Free Press 2006).

FASD and Indigenous populations in Canada

Many articles discussed concerns about increased prevalence of FASD in Indigenous populations compared to the general population in Canada. Several of those articles qualified that FASD has sometimes been incorrectly labeled an Indigenous-specific problem, since it can affect anyone. Several also discussed Indigenous people with FASD in the context of crime. Several more explored Indigenous awareness about FASD (e.g., "Aboriginals and adult women under 35 were the most likely to know the only cause of FASD is maternal drinking…" (Winnipeg Free

Press 2011)), or Indigenous knowledge being used to prevent FASD (e.g., "…Mrs. Whiskeyjack has been trying to revive the ancient mentoring role of aboriginal seniors… And her attempts to help curb the reserve's epidemic of fetal-alcohol syndrome seem to be working" (Vancouver Sun 2010)). Results about FASD-related discourse and Indigenous peoples in Canada are reported in a separate paper (Aspler et al., 2019). Race and ethnicity were not typically discussed outside of Indigenous contexts in this sample.

Impact of the social world on FASD

Stigma and Labelling

Some articles outlined concerns about the impact of stigma on women who drink while pregnant, as in the case of this 2002 article from the Winnipeg Free Press: "Punishing these women is not helpful, it further stigmatizes and shames them, which keeps them from reaching out for support". A few articles highlighted the positive impact the diagnostic label can have: "'To a certain extent, it was a relief, because now I knew what the problem was'" (The Globe and Mail 2003), while others focused on the negative: "When he was younger, the Jaffrays were reluctant to push doctors to pin an FAS diagnosis on him, worried it would act as a self-fulfilling prophecy for a lifetime on the margins of society" (Toronto Star 2002). A few articles reported concerns about the impact of media discourse connecting the label of 'criminal' to people with FASD: "The stigma of FASD has grown worse in Winnipeg in the last few years since it was associated with a string of auto thefts by local teens" (Winnipeg Free Press 2011). In one example, a young man explicitly commented on media discourse and sought to distance himself from the criminal label and stereotype: "…[FASD is] not as scary as you see in the media: 'These people are going to steal your car.' They're a very small minority of people with FASD… No one should label everyone with FASD as potential criminals or dupes eager to be recruited by gangs, he said" (Winnipeg Free Press 2011).

Socioeconomic Status

Some articles discussed how FASD is typically incorrectly thought to only affect people with lower socioeconomic status (SES), or how poverty can exacerbate the sources and impact of FASD: "'Poverty does magnify health risks. If you're poor, you have less access to nutrition and health care and likely more psychosocial stressors…. If it's [FAS], it's worse. But poverty doesn't cause [FAS]. Alcohol causes it'" (Globe and Mail 2003). Several articles also discussed how FASD affects people in wealthier socioeconomic brackets too: "Yet the label [of FAS] is still pinned most often on the children of poor… women… Invisible are the middle-class mothers who drink during their pregnancies, whose problems with the bottle are shamefully concealed behind closed doors… the expectant women most likely to imbibe are educated, older and of higher income" (Globe and Mail 2003). Some other articles discussed how diagnoses might differ across SES and racial dimensions, as in the case of the following article from the Winnipeg Free Press (2011): "Experts such as Chudley say it's likely doctors treating the troubled children of white, middle-class parents zero in on similar cognitive problems such as attention deficit hyperactivity disorder and never think about prenatal alcohol exposure".

Discussion

Stigma surrounding FASD affects many stakeholders, including individuals with FASD and their birth mothers, among others (Bell et al. 2015). Armstrong (1998), in a seminal paper, outlined the history of the construction of the diagnosis, observing how the early medical literature suggested "both the woman who drinks during pregnancy and her child are beyond hope and destined to be societal problems". Stigmatizing these groups could lead to difficult life trajectories for individuals with FASD (Bell et al. 2015) and blame, shame, or perhaps even criminalization for women who drink while pregnant (Armstrong 1998, 2003; Eggertson 2013; Hui, Angelotta, and Fisher 2017). Our analysis provides a first account of how FASD is presented in Canadian newspapers, which could contribute to stereotyped beliefs about both people with FASD and women who drink while pregnant. Through an analysis of articles published in ten top newspapers in Canada over the last 15 years, we identified eight themes related to social content (See Table 1). Across our results, we posit that the stereotype of 'the villain' dominated and connects to both key stakeholder groups.[5] We unpack this stereotype for both 1) people with FASD, for whom the 'villain' stereotype can be seen in the news coverage connecting them with criminal behaviour; and 2) women who drink while pregnant, whose 'villainy', while occasionally connected to disability discourse via discussion of substance abuse disorders, was most often built on the social expectations surrounding women and motherhood.

Stigma and People with FASD: The 'villain' stereotype

The most common disability stereotype we identified in Canadian FASD coverage was the villainous, immoral, or deviant disabled person. Twenty nine percent of our sample discussed a connection between FASD and criminal behaviour (See Table 1). This coverage did not always invoke stereotypes; in fact, some articles explicitly pushed back against the 'criminal' label or raised complex questions about culpability. However, the frequency with which the topic was raised, and occasional implied biological essentialism, could still provide fodder for stereotyping. Interestingly, it appears that the framing of people with disabilities as 'villains' is not universal across Canadian media. Haller et al.'s (2012) sample overlapped with ours to an extent (though broader, focused on all kinds of disabilities), including seven of the same sources and one shared

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[5] Other, less common stereotypes included people with FASD framed as burdens on families or on Canadian society (see Aspler et al., 2019), or as victims, the latter stereotype sometimes relating to the framing of mothers as villains – i.e., people with FASD were implicitly and explicitly framed as victims of their mother's behaviour.

year of coverage. However, while the victim stereotype appeared in both samples, the villain stereotype was not discussed in theirs, highlighting its potential specificity in the case of FASD.

In some fictional representations of disability, we can find instructive archetypal and extreme examples of the villain stereotype. *Peter Pan's* Captain Hook (Dahl 1993) and the *Lion King's* 'Scar' (his difference is marked by his name) are examples of characters whose physical impairments or differences are viewed as possible sources or manifestations of their villainy. As Dahl (1993) suggests: "It has been a convention of all literature and art that physical deformity, chronic illness, or any visible defect symbolizes an evil and malevolent nature and monstrous behaviour". Notably, roughly 10% of people with FASD have noticeable and characteristic facial differences (Andrew 2011) – potential fodder for such tropes. Similarly, fictional examples of intellectual disability and mental illness (e.g., Lennie in *Of Mice and Men, Batman's* The Joker), both of which can be elements of an FASD diagnosis, frame disability as a key source of a character's evil or unwittingly dangerous behaviour.

The specific case of mental illness is a useful analogue for better understanding some of the discourse surrounding FASD and criminal behaviour. Mental illness has been a key source of academic reflection on stereotypes and stigmatisation in both the news and entertainment media. While fictional examples can represent clear and extreme versions of stereotypes associated with disabilities, echoes of the same stereotypes can be seen in journalism (Babic et al. 2017). As a highly relevant and timely example, a common stereotype about mental illness and criminality focuses on mental illness as the cause of mass shootings, when causal factors and the commission of such crimes are far more complex (Metzl and MacLeish 2015). Indeed, beyond mental illness, Barnes (1992) notes that emphasizing "the connection between intellectual impairment and criminality are both common in the tabloids and the 'quality' papers".

Although offenders with FASD in our sample were never explicitly described as 'villains', it is hard to escape the implication that criminal behaviour is somehow unavoidable for people with FASD. "Secondary disabilities" like criminal behaviour are sometimes presented or understood as essential features of FASD. For example, Dej (2011) points to how children with FASD are initially perceived as "innocent victims worthy of intervention", until that perception shifts to an image of "undeserving and hopeless" criminals in adulthood. This hopelessness permeates our sample, connecting permanent brain damage to a lifetime of seemingly ineffective interventions and burdensome costs on Canadians (Aspler et al., 2019). Similarly, Robert Henry (2013) explores a troubling iteration of the FASD-criminal stereotype in the form of media narratives about an "FASD-gang link in indigenous communities".[6] At the same time, our sample included statements suggesting that the connection between FASD and criminal behaviour needs to be nuanced or reduced.

Culpability and policy approaches to FASD and criminal justice

Discussions about criminal culpability revolved around three distinct possible impairments: 1) a poor understanding of *consequences*; 2) a poor ability to reason about the rightness and wrongness of an *action*; or 3) no *intention* to harm, but issues with impulse control. However, there is a lack of clarity about what kind of "primary disabilities" may be relevant for understanding crime in the context of FASD. An understanding of FASD that accommodates difficulty understanding consequences could lead to conclusions about the effectiveness of jail as deterrence, as opposed to an understanding of FASD tied to intent, which might mean aiming for a charge of, for example, manslaughter over murder. Further research into the moral reasoning of

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[6] The stereotypes connecting Indigenous peoples in Canada to FASD persist, although as we reported, our sample did include some positive pushback. These FASD stereotypes move through other harmful stereotypes – including those of the 'drunk Indian'. For more on this topic, see Di Pietro and Illes (2014) as well as Aspler et al. (2019).

individuals with FASD could help clarify this issue; however, heterogeneity of the diagnosis could mean all three challenges exist across the spectrum. These complex questions about FASD and criminal culpability still typically rely on the assumption that some biological feature of the disorder alone inevitably leads to criminal behaviour – rather than complex combinations of individual and social factors (e.g., foster care, impairment, police training).

Discussions about the relationship between FASD and criminal behavior must tread cautiously or risk cementing essentialist accounts of people with FASD as inherently criminal. For example, in the 2014 hearings for federal bill C-583, a bill to amend the criminal code to consider an FASD diagnosis as a mitigating factor in sentencing, some witnesses suggested that the bill could constitute discrimination: "…[this] is likely to further create associations between FASD and criminality which will only serve to further stigmatize this condition" (Standing Committee on Justice and Human Rights 2015). While better accommodating FASD in a criminal justice context should be a priority, and amending the criminal code could ultimately be a good solution, we must remain sensitive to concerns that our efforts to help people with FASD, through policy or otherwise, may perpetuate the stigma we seek to minimize.

People with FASD: villains and victims both

In our sample, 8% of the articles framed people with FASD as either victims of crimes or as more likely to become victims than other groups. Implicit in these and other discussions was a dual narrative, seen elsewhere in the FASD literature, which shifts the framing of individuals with FASD from sympathetic child or adolescent victims to hopeless adult villains (Dej 2011). The victim framing, though prevalent in the context of crime, also appeared in relation to women's drinking behaviour. A similar media study about alcohol and pregnancy in the US found three dominant frames: 1) *dangerous mothers*, about women's behaviour while pregnant (similar to the stereotype found in our analyses); 2) *fetal wellness*, which provided health advice; and 3) *victimization*, about the complex relationships between the identities of women who drink while pregnant and their children with FASD (Connolly-Ahern and Broadway 2008). In the case of the third theme, the children were seen as victims of their mothers, while those children as adults were seen as 'villains' as well – victimizing others, now as criminals with FASD.

Stigma, FASD, motherhood and villainy

Unlike coverage in the US, which mentioned women on trial or arrested for "fetal abuse" (Connolly-Ahern and Broadway 2008), we did not find reports of Canadian women who drank alcohol during pregnancy being arrested or receiving other forced interventions. Despite a few op-eds calling for harsh punishment,[7] the interventions reported were mostly potential support programs for at-risk women. In fact, the Canadian media effectively communicated a number of nuanced counter-narratives, including how it is important for women to be able to receive support in non-judgmental environments, or that women typically do not drink while pregnant with the aim of harming their fetus.

However, in coverage about and interviews with adoptive or foster parents, *mothers* were still most often the focus – even when their partners were described as supportive – in line with concerns about women being held more responsible for the wellbeing of their children. In one example, the parents are referred to as "Carol and her husband", explicitly detaching the father from his fatherhood, seemingly shifting the entirety of parenthood onto the interviewed mother.[8] It is also interesting that none of the stories about fathers who themselves have FASD, though

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[7] In Aspler et al., (2019), one theme (treatment of FASD) included examples of how we should treat women who drank while pregnant. In an op-ed from the Calgary Herald (2005), one reader articulated an extreme position, suggesting that "these doped-up druggies should be sterilized after the second child…"

[8] Admittedly, Carol is an anonymized individual given a pseudonym for the article; however, the husband is not even given an anonymous identity outside of his relationship to Carol.

admittedly small in number, were framed negatively, while the examples about mothers with FASD were almost entirely negative. The stories about fathers involved overcoming issues like drug abuse, finding jobs, and achieving a stable family life. In contrast, the negative stories about mothers with FASD explored the perpetuation of cycles of alcohol abuse leading to children who themselves also have FASD. It is striking how the responsibilities of fathers, when mentioned at all, were rarely covered.

Furthermore, we can point to articles that described experiences of shame, and fear of judgement or punishment, to indicate that presenting information about FASD in certain ways can have a negative impact on some women. Under the socioeconomic status sub-code, nuanced concerns were raised about the problematic stereotyping of mothers of children with FASD (e.g., as poor, as indigenous); however, the pushback against these stereotypes contained in our sample simply expanded the label of 'bad mother' to encompass all women from all walks of life and rarely explored broader concerns about community responsibilities, intersectionality, or partner-inclusive or even partner-focused prevention messages.

Our results are therefore consistent with observations made by Armstrong (1998) that the responsibility for FASD often falls directly on the shoulders of women alone. In the 1970s and 1980s, when the diagnosis was first constructed, a "conservative political climate" likely contributed to centering the conversation about FASD on personal responsibility (Armstrong and Abel 2000). Although the diagnosis initially focused on the children of "chronic alcoholic women" alone (Jones et al. 1973), researchers and clinicians soon expanded the definition to suggest "that any drinking by any pregnant woman was dangerous" (Armstrong 1998) – a narrative we still see in individual-focused abstinence-based public health messages (Zizzo and Racine 2017). Armstrong (1998) points to early medical writing about "fetal alcohol syndrome"

(FAS)[9] that frame women who drink while pregnant as having "clearly failed to fulfill their roles as nurturers", even when trouble nurturing was connected to factors typically understood as outside of one's control (e.g., disease, trauma). In many different ways, even in complex circumstances, women who drink while pregnant were and continue to be perceived as guilty for failing to protect their children. Armstrong (1998), perhaps controversially, ultimately suggested that "moral fervor powered the discovery of [FAS] as much as medical curiosity".

These narratives of responsibility lend themselves to commonly described frames of the 'dangerous' or 'bad' mother (Connolly-Ahern and Broadway 2008; Lowe, Lee, and Yardley 2010). Although not directly related to the history of the villain disability stereotype, framing women as bad or dangerous mothers certainly connects them to some kind of villainy. These kinds of attitudes, at least in certain jurisdictions in the USA (Paltrow and Flavin 2013), can be connected to punitive policies aimed at pregnant women – which have led to arrests and even forced interventions (Drabble et al. 2014; Hui, Angelotta, and Fisher 2017; Racine et al. 2015). Although such measures have not made their way into Canada, where substance use is not illegal during pregnancy (Hui, Angelotta, and Fisher 2017), similar negative and stigmatising attitudes underlie some possible policy and healthcare approaches, as well as some media coverage in our sample. Concerns in Canadian newspapers remain focused on subtler messages about individual responsibility, but still without emphasizing the importance of community support, social circles, or the role of the woman's partner. This will not necessarily lead to punishment, but it can certainly generate public blame and private shame for pregnant women in need of support.

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[9] At the time Armstrong published her first article, the term FASD did not yet exist. The spectrum as a medical diagnosis was still being constructed, so she refers mostly to the original term "fetal alcohol syndrome". She does, however, highlight concerns about the diffusion and widening of symptoms and descriptions of FAS (1998).

Limitations

This study has several limitations. First, we only included articles where keywords were present in the headline or lead paragraph to ensure that FASD, or alcohol and pregnancy, were central to the stories we analyzed. This could have excluded additional articles about themes like crime, for example, if a suspect was only connected to FASD in a later paragraph. Second, in including only the top 10 English-language newspapers in Canada, our sample focused on stories from certain cities (i.e., Vancouver, Edmonton, Calgary, Winnipeg, Toronto, Ottawa, Montreal), while excluding coverage from other major parts of the country (i.e., the North, Saskatchewan, and Atlantic Canada). There might have also been some local coverage we missed from smaller papers, towns, or reserves in the provinces from which we did have representation.

Third, we tried to sample major French newspapers in Canada; however, Factiva began archiving *Le Journal de Montréal* and *La Presse* starting in 2011. While we do not know if these sources discussed FASD before 2011, no articles were found from 2011-2015. This could help explain differences in knowledge across Canada (based on Canadian surveys), since respondents from Quebec were less aware of FASD compared to other Canadians (Environics Research Group 2006). It may also be caused by differences in attitudes toward drinking in different regions of the country (April and Bourret 2004). More research is needed to understand such regional and cultural differences. In addition, three other included sources suffered from gaps in database coverage: 1) the *Edmonton Journal* from Feb 2002 – Dec 2003; 2) the *Toronto Star* for 2003; and 3) the *Vancouver Province* before Sep 2008. As a final note about sources, as of 2010, six of ten newspapers were owned by a single corporation (Postmedia), and, prior to this, at least five of ten were owned by Canwest (2000-2010). Postmedia ownership explains a large segment of the cross-posted duplicates included in this sample.

Conclusion

Our analysis of Canadian newspaper articles discussing the social dimensions of FASD identified eight key themes: 1) crime associated with FASD; 2) more support needed for FASD stakeholders; 3) awareness of FASD; 4) family composition of people with FASD; 5) funding for FASD; 6) FASD and Indigenous populations in Canada; 7) secondary disabilities associated with FASD; and 8) impact of the social world on FASD. We explored our results through the process of stereotyping and stigma as applied to two key stakeholder groups: 1) people with FASD; and 2) women who drink while pregnant. The literature on disability stereotypes, notably the stereotype of 'the villain' and to a lesser extent 'the victim', helped us to better understand Canadian coverage of FASD. The victim stereotype related in turn to stereotyped expectations of motherhood – as in, people with FASD are seen as victims of women who drink while pregnant. Not all of the coverage in our sample reflected these stereotypes; indeed, some articles sought to challenge them. Looking forward, the mechanisms of stigma at work in the context of FASD should be further explored as well as their implications for people with FASD and mothers of children with FASD. Otherwise, well-intended public awareness campaigns and media coverage risk fueling stigma against those people whose health and wellbeing they aim to promote.

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Concluding remarks for Chapter 4: Media disability stereotypes and FASD

In this paper, we explored challenges associated with human interest stories on disability, the news portrayal of people with FASD and women who drink while pregnant, and the social construction of FASD and motherhood. A plethora of media analyses in Canada and globally have explored the concept of disability, identifying troubling narratives, tropes, and stereotypes that reflect the stories a society chooses to tell – or not to tell – about people with disabilities [34, 35, 150-156]. Integral to these studies is "concern about how what we may be seeing may impact individuals and society overall" [156]. Here, we found that people with FASD were represented hopelessly, associated with negative stereotypes like the *victim* or the *villain* – as hopelessly tragic or as irredeemably deviant. While some coverage unpacked or critiqued these narratives to provide a more balanced or complex account of FASD, we identified no stereotyped portrayals that connected FASD to the *hero* or the "supercrip" stereotype, again emphasizing a negative stereotyped portrayal. This contrasts some preliminary research I conducted when I began my thesis that explored the representation of people with cerebral palsy (also a neurodevelopmental disability) in Canadian print news [157]. Unlike in our work on FASD, we identified competing narratives of triumph (*heroes*) and tragedy (*victims)*, and a set of news articles that more often emphasized human interest over science and health communication, as well as individuals with heterogenous challenges and needs. This media coverage also contained stereotyped portrayals (notably conflating motor difficulties with intellectual disability) [158], but it aligned with the most common disability stereotypes identified in news coverage broadly [35, 156], unlike FASD, which presented a uniquely skewed set of stereotypes pointing exclusively at the negative. It was the above "concern" about how what we see could impact society that led us to conduct focus group interviews about FASD and motherhood in the news (both tied in different ways to crime).

SECTION OVERVIEW: Focus group interviews: Chapters 5 to 7

Chapters 5 and 6 contain manuscripts on our focus group project that address Objectives 2 and 3: To learn about experiences and perspectives of FASD stakeholders and to understand their views on Canadian coverage of FASD, alcohol, and pregnancy. Manuscript III (Chapter 5) published as *"It's ignorant stereotypes": Key stakeholder perspectives on stereotypes associated with fetal alcohol spectrum disorder, alcohol, and pregnancy,* focused on experiences with FASD and alcohol-related stereotypes, and their potential or felt impact. Manuscript IV (Chapter 6), titled *Hope, Inclusion, Education, Community, and Fear: Stakeholder recommendations for public discourse about FASD, alcohol, and pregnancy reports on reactions to news content and recommendations for improvement*, explored participant recommendations to improve discourse and the evidence for and ethics of different communication tactics. Both papers build on the manuscripts in Chapters 3 and 4. Similarly, Chapter 7, a personal and reflexive book chapter titled *Making research more ethical for adults with FASD: A story of stakeholder engagement, accommodation, and inclusion,* addresses the methodological and ethical challenges we faced in recruiting participants with FASD across various urban centres in Canada. It effectively captures the nuances of recruitment in a way that the empirical manuscripts could not. We collected and analyzed more data than we could present in manuscripts and this thesis alone. See Appendix 1 for study materials (ethics approval, outreach, screening questionnaire, informed consent form, confidentiality agreement, interview grid, and coding framework). See Appendix 2 for data tables that help paint a more holistic picture of focus group discussions and the lives of participants. As discussed in Chapter 2, the theory, concepts, and values informing this research require a deeper understanding of participants and their situations – these tables help flesh out the narratives woven across this thesis and those recounted by our participants.

CHAPTER FIVE – FASD STAKEHOLDER EXPERIENCES OF AND KNOWLEDGE ABOUT STEREOTYPES AND STIGMA

Manuscript III: "It's ignorant stereotypes": Key stakeholder perspectives on stereotypes associated with fetal alcohol spectrum disorder, alcohol, and pregnancy

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Abstract

Background: People with fetal alcohol spectrum disorder (FASD) and women who drink alcohol while pregnant can experience stigma, possibly exacerbated by stereotyped media portrayals.

Method: To understand experiences of FASD stakeholders and reactions to news coverage, we conducted twelve focus groups across three categories: (1) people with FASD; (2) caregivers; and (3) professionals. Themes were identified using framework analysis.

Results: We identified stereotypes about: (1) FASD (e.g., negative life trajectories); (2) alcohol and pregnancy (e.g., bad mothers); and (3) non-biological caregivers. Participants identified potential effects of FASD stereotypes (e.g., self-fulfilling prophecies) and alcohol and pregnancy stereotypes (e.g., exacerbating difficult decisions about disclosing a child's adoptive status).

Conclusions: Our results align with research about difficult experiences of FASD stakeholders. However, while Canadian news analyses found people with FASD portrayed as criminals, our participants identified mostly non-crime stereotypes. Participants also sometimes shifted the burden of motherhood stereotypes from low-income to higher-income women.

Keywords: FASD; stigma; stereotypes; alcohol and pregnancy; motherhood; framework analysis

People with fetal alcohol spectrum disorder (FASD), a complex neurodevelopmental disability resulting from alcohol exposure in the womb, can have difficult life trajectories (Bell et al., 2015). In addition to living with various impairments (e.g., in mood regulation, motor skills, executive function) (Cook et al., 2016), people with FASD report stigmatising experiences, including social exclusion and employment discrimination (Salmon & Buetow, 2012; Stade et al., 2011). Similarly, mothers and women who drink while pregnant can experience stigma given the link between alcohol, pregnancy, and fetal impairment. This kind of maternal stigma can lead to feelings of shame and blame – or even to criminalisation (Armstrong, 1998; Eggertson, 2013). These challenges require a deeper understanding of the perspectives of key FASD stakeholders, which our study aims to provide – especially regarding stigmatisation and solutions to stigma, grounded in stakeholders' complex lived experiences (Racine, 2016).

Experiences with FASD

Several studies have explored the experiences of FASD stakeholders (Domeij et al., 2018); however, most have focused on the perspectives of family and caregivers – relatively few have included people with the diagnosis. In a review of qualitative literature on people with FASD and their caregivers, Domeij et al. found that only two of eighteen studies included people with FASD. The findings highlighted some common experiences for people with FASD: difficult circumstances and daily challenges (Salmon & Buetow, 2012), feeling different and socially isolated (Stade et al., 2011), and a lack of support (Ryan & Ferguson, 2006). However, some people with FASD did report positive experiences of feeling cared for by parents (often adoptive), who served as key advocates (Duquette et al., 2006).

Parents of people with FASD may also experience a range of difficulties as biological, adoptive, foster, or kinship caregivers. Parents manage care for a child with impairments – and grief associated with a diagnosis – while biological mothers additionally contend with guilt and judgement from others (Salmon, 2008; Sanders & Buck, 2010). However, such diagnoses can also help parents feel relief at having an explanation for their child's behaviours. Importantly, parents may also feel they lack support (especially from professionals) (Whitehurst, 2012), taking up the role of advocate (Duquette et al., 2006). While often proud of their child's accomplishments, parents in almost every study expressed concern about their child's future.

FASD in the news and key stakeholder perspectives

This study builds on a previous media content analysis of Canadian print news coverage of FASD, alcohol, and pregnancy (Aspler, 2019; Aspler et al., 2018; Aspler et al., 2019). That study found exaggeration about the prevalence of FASD in Indigenous communities, stereotyped portrayals of people with FASD as criminals, and a lack of social context for maternal alcohol consumption. Based on the findings, we aimed to learn about the experiences of Canadian FASD stakeholders and understand their perspectives on related news coverage. Here, we present data from focus groups with three stakeholder groups: (1) people with FASD; (2) their adoptive, foster, or kinship caregivers (CGs); and (3) relevant healthcare and allied professionals (HCAPs).

Conceptualizing stigma

According to Link and Phelan's landmark theory of stigma (Link & Phelan, 2001), stigmatisation can be characterised by five co-occurring elements: (1) labelling differences (e.g., an FASD diagnosis); (2) attributing stereotypes to labels (e.g., all people with FASD are criminals); (3) othering the labelled and stereotyped group (e.g., jailing rather than supporting people with FASD); (4) status loss or discrimination (e.g., people with FASD may be jailed at higher rates than the general population) in the context of (5) power aligned against them. Of these elements, we asked participants to reflect on their experience of diagnostic labelling and their familiarity with stereotypes around FASD, alcohol, and pregnancy. Given the connection of this work to a previous media analysis, the labelling and stereotyping elements of this model were deemed most salient in relation to science and health communication. In addition, we sought experiential data as further validation of parts of Link and Phelan's model.

In their model, stereotyping means that "dominant cultural beliefs link labelled persons to undesirable characteristics – to negative stereotypes" (Link & Phelan, 2001). It is these undesirable characteristics that have been central to understandings of stigma since Erving Goffman explored the notion of "spoiled identity" in his seminal text on *Stigma* (1963).

In this paper, we report a portion of our interview data: the portion on stereotypes. We focus primarily on concerns about the potential impact of stereotypes on marginalised groups – negative stereotypes that could lead to the "spoiling" of identity and discrimination. There also exist other kinds of stereotypes (e.g., positive stereotypes – described in the methods below), which can still have a negative impact. Importantly, as we articulated in a separate paper:

> … while the goal of much research is to create generalizable knowledge, there exists a fine line between appropriately generalized claims and inappropriate exaggeration. When those claims begin to impact the social world, and beliefs about particular groups of people, there exists a danger of endorsing positions that turn generalizations into stereotypes. (Aspler et al., 2019)

This paper fills some potential gaps in research (Choate & Badry, 2019; Domeij et al., 2018), by including a cross-section of key FASD stakeholders in Canada in one study (especially adults with FASD, who have not often been included in qualitative work) to explore stigmatisation, stereotypes, and their felt impact.

Methods

We conducted semi-structured focus group interviews with three key stakeholder groups. Our study design, an interdisciplinary health research approach (Gale et al., 2013), incorporates theory and methods from bioethics (Racine, 2016), disability studies, and sociology (Link & Phelan, 2001). Focus groups enable solidarity among people with similar experiences, to allow a more open discussion on sensitive topics (Lunt & Livingstone, 1996). A multi-category focus group design, where each focus group included members from one stakeholder group, enabled us to compare within and across connected yet distinct groups (Morgan & Krueger, 1998).

Ethics approval

This study was approved by the Montreal Clinical Research Institute's research ethics board, in accordance with Quebec and Canadian (Canadian Institutes of Health Research et al., 2014) ethics guidelines.

Sampling

Our three stakeholder groups included: (1) adults with FASD; (2) caregivers for people with FASD; and (3) relevant healthcare and allied professionals. We included participants with or without an official diagnosis; as in, some of our participants self-identified as having FASD. We included a range of HCAPs (i.e., physicians, nurses, social workers, psychologists) across diverse domains (i.e., diagnostics, criminal justice, healthcare, addiction, child welfare).

We excluded participants who we and local support staff felt might not understand the questions, or who were at greater risk of experiencing distress given the sensitive topic. We also excluded people who were not proficient in English (since the discussion prompts came from English-Canadian print news), children, and people not located in Canadian cities to which we could travel and form focus groups.

Finally, some participants had identities that crossed multiple categories (e.g., a person with FASD who had a child with FASD, an adoptive parent with professional training). In these cases, we asked participants to choose their preferred category – the one with which they identified most – and to keep that perspective in mind when answering questions.

Recruitment

We recruited participants through purposive and snowball sampling from several major urban centres across Canada. We first recruited HCAPs by advertising the study to members of a national network of researchers and clinicians (NeuroDevNet, now called Kids Brain Health Network (KBHN), a Network of Centres of Excellence of Canada focused on FASD and neurodevelopment). Then, these professionals referred us to FASD community groups and their own professional networks. Members of these communities helped us organise focus groups (Aspler, 2019). Concurrently, and with the help of those groups, we circulated flyers online.

Interested participants were invited to contact JA by phone or email, to ask questions, and to complete an online demographic questionnaire regarding their relationship to FASD (e.g., age of diagnosis) and stakeholder group. After receiving completed surveys, we contacted potential participants to ensure their capacity to consent and to build meaningful relationships.

Participants

We conducted 12 focus group interviews – four with each stakeholder group – with 4-8 participants each. A total of sixty-three people participated in the focus groups: 19 adults with FASD, 20 CGs, and 23 HCAPs. We also conducted a one-on-one interview with a biological father, who did not fit other categories. Notably, besides several people with FASD who were also mothers of children with FASD, we were unable to recruit birth mothers; the CG participants were all adoptive, foster, or kinship caregivers.

Participant confidentiality

Before each focus group, participants were asked to sign a confidentiality form. Participants were reminded that they were invited to share their own stories or experiences of the focus group, but not other people's stories. We also coded participant identities. Only the authors and transcriptionist had access to audio recordings and deidentified documents. We attribute quotes using pseudonyms and stakeholder category (i.e., Emily, CG) and the specific focus group within their stakeholder category (i.e., CG1 through CG4)

Participant demographics

Most participants (52/63) were women (82.5%): 21/23 HCAPs (91.3%), 17/20 CGs (85%), and 14/19 people with FASD (73.7%) – though we also had one biological father. The two male HCAPs were the only physicians who participated. The remaining HCAPs were nurses (n=1), service-oriented researchers (n=2), psychologists (n=3), and social workers (n=15). We interviewed participants in four major Canadian urban centres across two Canadian provinces.

Semi-structured focus group interviews

Focus group interviews were conducted in English, audio-recorded, and transcribed verbatim by a professional transcriptionist. The first author (JA) moderated the discussions while the second author (AB) took notes. AB was also available in her professional capacity as a social worker if support needs arose during interviews.

Interview Grid

JA designed the interview grid with the assistance of ER based on Link and Phelan's model of stigma and the results of our media analysis. A first draft was shared with FASD scholars and professionals from KBHN. We also provided drafts to several parents of children with neurodevelopmental disabilities to assess appropriateness and complexity. Early in the study, we received critical but necessary feedback from a group of adults with FASD who felt that our interview questions were too abstract, our media prompts too negative, and that support post-interview was lacking – especially since we left most cities once the interviews ended. This greatly improved our protocol (see Aspler, 2019): In short, we simplified the text of the questions and, crucially, we worked with community organisations to safely recruit and support local participants with FASD before, during, and after the interviews.

Interview Questions

We asked participants questions about their experiences with diagnosis; stereotypes about people with FASD and birth mothers; and how they felt about certain media (Aspler et al., 2018, 2019). In this paper, we report results about stereotypes, specifically. In the interview, we provided participants with a definition of the term stereotype[1] and asked them about its potential application to people with FASD or to women who consume alcohol while pregnant. We also asked a follow-up question on whether these stereotypes had ever impacted or could hypothetically impact the lives of our participants or people like them. For HCAPs, this follow-up referred to their knowledge of their patients' or clients' real or possible experiences, as well as any personal or professional impact they have or could have experienced in their work.

Interview Analysis

Developed by Ritchie and Spencer (1994), framework analysis includes five steps (Gale et al., 2013): (1) data *familiarisation*; (2) *thematic analysis* for coding framework development;

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[1] "Stereotypes are common ways to describe entire groups of people (like men or women), even though there are huge differences between each individual. For example: saying that all women like the colour pink ignores the fact that plenty of women do not like pink at all. Stereotypes can also seem positive, like saying that some groups of people are always very clean, or negative, like saying that some groups are always messy."

(3) *indexing*, a systematic application of the framework to the sample; (4) *charting* summarised data into tables to compare between and within participants across themes; and (5) *mapping and interpretation* a visual exploration of relationships between themes.

One coder (JA) *familiarised* himself with the data by listening to and reading each transcript multiple times, and by recording voice memos. Two coders (JA, AB) then annotated three transcripts separately (one from each stakeholder group), identifying emerging themes for a *coding framework*. After each transcript, the two coders discussed their results. A third coder (ER) then reviewed transcripts, assessing the themes developed by the first two coders, providing feedback and resolving disagreements. This process was repeated with three additional transcripts to finalise the coding framework, and then JA *indexed* the final seven transcripts (six focus groups and the single one-on-one interview) alone in MaxQDA, returning to the other coders to discuss new or emergent themes and resolve issues as needed. This ensured an iterative and comparative process, so the finalised framework could be applied back to the first transcripts that had been used to build the initial framework. The final indexed data was reviewed at the end by ER. Finally, JA *charted* the data by exporting and rearranging the MaxQDA data in Microsoft Excel, which was also used to *map and interpret* the results across different groups.

Results

The results reported in this manuscript reflect three stereotype categories identified in the coding framework: (1) *Stereotypes associated with FASD*; (2) *Stereotypes associated with alcohol and pregnancy*; and (3) *Stereotypes associated with non-biological caregivers for people with FASD* (Tables 1–3 respectively). Additionally, within each category, we present participant views on the felt or hypothetical *Impact of stereotypes*. Each table includes a definition of each code and subcode, a list of stereotypes, and illustrative examples. After each table, we include additional observations, in text, about which stakeholder group(s) emphasised which stereotypes, and how participants discussed them. Notably, the first two categories emerged in response to questions we asked, while the third emerged organically as CGs reported additional concerns. Note that some stereotypes emerged in response to media prompts, which we specify.

Stereotypes associated with FASD

We found two categories of stereotypes associated with FASD (Table 1): (1) *Ability expectations* regarding what people with FASD can or cannot do; and (2) *Expected life trajectories* regarding assumed adverse outcomes in specific demographics. We also describe two categories of FASD stereotype impact: (1) *Feeling unsupported*, where stereotypes limit support; and (2) *Self-fulfilling prophecies* regarding stereotypes impacting the actions and self-esteem of people with FASD. Importantly, some participants argued that "[n]obody knows enough to have a stereotype" (Jennifer, CG3): "When you asked the question, I thought, 'Wow, it would be nice if there was a stereotype'. I mean, you know… that at least people would understand the disability enough that they could give a [stereotype]…" (Lee, HCAP2).

Table 1: Stereotypes associated with FASD and their impact

FASD stereotypes	Illustrative examples of FASD stereotypes
(Dis)ability expectations: People with FASD *can* or *cannot* do certain tasks (to the point of hopelessness), or they have specific intellectual or behavioural limitations. Also linked to the expectation that FASD is always *visible* (i.e., people with FASD "look normal" so should be capable of acting or performing in "normal" ways, or concerns that it is just an "excuse" for bad behaviour; that FASD is only "real" if visible). Also includes the idea that people with FASD are *bad* people.	*Expectations that a person with FASD* can *do certain tasks:* "...because they are considered to be of average intelligence… the expectation is that they are capable of doing everything correctly, and because they can't it's creating huge problems…" (Amaya, CG2). *Expectations that a person with FASD* cannot *do certain tasks:* "…you're asking about stereotypes, I think one of the things that people think about is… people with FASD aren't necessarily able to live independently or have issues with functioning in their day-to-day life" (Angela, HCAP3).

	The expectation that FASD is always visible: "…it's really misunderstood…it's just so generalized… you look completely normal on the outside, but there's like a million things on the inside that just don't align, don't add up, don't make sense to the normal general population. And it's really hard when you have to try to jump into normal society. And I hate using that word, 'normal', but that's the only way I can say it. It's like, in a lot of my life, I haven't felt normal" (Christina, FASD4). *The expectation that people with FASD are bad:* "And no matter what I did to try and better myself, it never worked because the teacher's like, 'Oh, you're a problem child.' So, they automatically just boom, you know? 'You're stupid. You don't know how to do this. You don't know how to do that.'" (Leila, FASD3).
Expected life trajectories: That people with FASD will experience certain adverse outcomes, especially when tied to certain demographics – i.e., that people with FASD are *low-income, adopted*, *Indigenous, criminals* and/or *substance users*.	*Expected income-level/adoptive status:* "I wonder if stereotypes about poverty and lower class or income people having FASD comes from the fact [of child welfare's] involvement with kids is a lot of kids with FASD, and there's not a lot of [child welfare] involvement with upper middle-class families" (Asha, HCAP2). *Expected connection to Indigenous communities:* "Must be Native. [My child's] not Native" (Noor, CG4). *Expected criminal behaviour:* "Well, I think just in terms of talking about FASD, often people equate it with things like the justice system, or, you know, housing… So, for example, they might assume that individuals with FASD, you know, either drink a lot, do drugs, you know, commit crimes" (Cameron, HCAP4). *Expected substance use:* "Yeah, that all people with FASD have alcohol dependency. So, we're all alcoholics… that it's really hard to break the cycle. Like, since we were born on alcohol that we are going to drink when we're pregnant" (Riley, FASD1).

Impact of FASD stereotypes	Illustrative examples of the impact of FASD stereotypes
Feeling unsupported: Professionals, from teachers to physicians to social workers, may endorse stereotypes about FASD (e.g., that people with FASD *cannot* succeed*)*, which leads to people with FASD or families feeling or being unsupported, like they have been "given up on".	"I think one of the biggest ones that I deal with… is that individuals with an FASD can't learn, can't grow, their brains can't change, they can't use strategies, things like this that essentially describe the brain injury as very rigid and very permanent… [W]e see now in places where different service providing agencies restrict access to individuals with an FASD because they won't benefit from the service, 'they have an FASD'" (Morgan, HCAP1).
Self-fulfilling prophecies: That negative media stereotypes (prompted by news quotes), from *crime* to *intellectual limitations* to *cannot* succeed could lead people with FASD to internalise those stereotypes and perhaps even act on them by meeting those expectations.	"…saying… anybody with FAS or FASD is going to be a criminal. They're going to, you know, go rob a bank… steal a car or something… yes, some of us will get into that… [but] I find that stereotyping stuff like that…that gets into our heads, and then we start feeling, well, because people say that, well, now we have to be like that" (Summer FASD4). "I'm thinking if the person with FASD was to read any of these, because abstract thinking is so challenging for them, they might internalize that and then say 'I am going to be recruited by a gang or I am a criminal' and that is dangerous in itself" (Mackenzie, CG1).

How participants discussed FASD stereotypes

Most participants rejected stereotypes by arguing that they could affect anyone. For example, that a person need not be Indigenous to have FASD, or that people without FASD commit crimes. Participants also provided alternate explanations for perceived stereotyped behaviours (e.g., laziness) based on personal experiences, pointing to how others might misinterpret certain behaviours as fodder for stereotyping, rather than as an indication of the need for greater accommodation.

A contradiction that emerged, usually in CG groups, were contrasting stereotypes about a person with FASD's ability to improve certain behaviours. Most participants strongly rejected hopeless stereotypes suggesting people with FASD cannot succeed or learn. However, many CGs appeared frustrated when support systems or actors (e.g., teachers) failed to understand that their child's "permanent brain damage" (language used by several CGs and HCAPs) meant they could not improve or perform in expected ways. These were not mutually exclusive ideas – with appropriate support and accommodations, people with FASD can succeed, even if they continue to face challenges – but they point to potentially contradictory stereotypes: that people with FASD are not expected to succeed, improve, function, or do anything, while simultaneously being expected to perform "normally" given how "normal" (language used by participants in all categories) most look, given the invisibility of a diagnosis like FASD.

Endorsing some FASD stereotypes

Very few FASD stereotypes were endorsed by participants. However, a few cross-group differences existed, as when one CG reported that their child lacked empathy. In contrast, one person with FASD described "no empathy" as a stereotype, and empathy as a strength. Tension also emerged when endorsement was rooted in lived experience – e.g., one CG who disagreed with others that FASD does not always mean "mentally challenged" since "my [child]'s mentally challenged!" (Jennifer, CG3).

Distinguishing between stereotypes specific to FASD and broader disability stereotypes

Some CGs tied the idea of "[n]obody knows enough" to how stereotypes impacting their children are more about disability in general than FASD specifically. For example, one CG argued that: "…they may pick up the word 'disability'… 'well, [they] can't do that... [they have] a disability'… 'children with a disability… can't handle that'" (Mo, CG2). In another case, when a parent said that FASD stereotypes have led to bullying at school, additional prompting revealed that the stereotypes were not FASD-specific: "[Other kids] did not know that he had [FASD] and he refused to ever let them know, right or wrong" (Emily, CG1).

Stereotypes associated with alcohol and pregnancy

We found three categories of stereotypes associated with alcohol and pregnancy (Table 2): (1) *Demographic expectations* regarding who drinks during pregnancy (e.g., low income); (2) *Behavioural expectations* about what they might have done (e.g., heavy drinking); and (3) *Character expectations* reflecting judgemental attitudes (e.g., bad mothers). We also describe two categories reflecting the impact of alcohol and pregnancy stereotypes: (1) *Adoption disclosure* regarding the impact of birth mother stereotypes on adoptive CGs (i.e., disclosing that they are not the birth mother to avoid judgment); and (2) "*Can't happen to me"* (Amaya, CG2) regarding concerns that some women might employ negative stereotypes to distance themselves from FASD (e.g., high-income women assuming it can only happen to low-income women).

Table 2: Stereotypes associated with alcohol and pregnancy, and their impact

Alcohol and pregnancy stereotypes	Illustrative examples of alcohol and pregnancy stereotypes
*Demographic expectations: A*ssumptions about the kind of woman that is most likely to drink during pregnancy based on *income level*, *ethnicity*, *age*, *education*, and *substance user status*.	"…the typical stereotype is that certain groups are much more likely to drink when they're pregnant… Aboriginal groups, substance users, teens… when people think of FASD, they think of those groups first" (Isabella, HCAP4).
Behavioural expectations: Assumptions that birth mothers must have behaved in certain ways while pregnant (e.g., drinking heavily). Overlaps with *FASD stereotypes*: That pregnant women with FASD are trapped in *intergenerational cycles of substance use*.	"…they think the birth mother must have been drinking an awful lot and it is often because the people you're talking to, I think themselves, often had been drinking a small amount in pregnancy and they don't want to deal with those thoughts so I think they are trying to make themselves feel better too by saying 'she must've been a really heavy drinker'" (Emily, CG1).

	Intergenerational cycles of substance use “They automatically assume that just because you have it you drank, and you’re going to give it to your kid” (Leila, FASD3).
Character expectations: Assumptions about the character or culpability of women or birth moms who consume(d) alcohol while pregnant (e.g., selfish, uncaring, bad, unfit, blameworthy), about whom some may wonder “how could [she] do that”, “didn’t she know not to drink”, or for whom drinking and having a child with FASD was a “choice” done “on purpose”.	“…[Y]ou have a kid with FASD. What do people say to you about that… ‘Oh, it’s all your fault. You’re a bad mum’ Right?” (Courtney, FASD3) “Well, just out of control or uncaring or something like that” (Robert, CG4) “That they have the ability to make the choice… the assumption is that everybody can just make that choice and stop” (Kala, HCAP1).
Impact of alcohol and pregnancy stereotypes	Illustrative examples of the impact of alcohol and pregnancy stereotypes
Adoption disclosure: Stereotypes about birth moms tied to responsibility and blame seemed to create tension and a fear of judgement for CGs in relation to decisions about whether to disclose their child’s adoptive status. One HCAP raised this concern briefly, connecting it to poor care provision. Another HCAP mentioned the interaction of certain demographic expectations with adoption disclosure.	“I had one person say to me ‘oh, are you dealing with addiction issues?’ That was when I was brave and didn’t say I was an adoptive parent. Yeah, it is a tricky one to not put that word ‘adopted’ in there too” (Emily, CG1). “…[they] took their adoptive daughter to the emergency department… the staff didn’t know that the child was adopted [but did know the child had FASD], and their attitude… was awful, and as soon as the adoptive parents said, “You know, our child is adopted 100 percent,’ a 360 change into, ‘Oh, well, so you’re not the parents who caused this’” (Lee, HCAP2). “I had a client who was First Nations herself… [who] became an adoptive parent… she would say to me, ‘Oh my gosh, now everybody’s going to think I did it because I’m Indian’ (Cameron, HCAP4).

"*Can't happen to me"*: Some CGs argued that *demographic* or *behavioural* stereotypes could impact perceptions about the harm or acceptability of alcohol consumption during pregnancy.	[In response to media prompts]: "…if you're not a Native person then, it's like, oh, you can't have FASD, which is not true at all and sort of prevents those people from getting help… I can see… a professional… mother who finds out her child has FASD saying 'Oh my gosh, I thought only mums who were falling down drunk would have a child with FASD'" (Patricia, CG4).

Differences in stereotypes about alcohol and pregnancy across stakeholder groups

All stakeholders discussed each alcohol and pregnancy stereotype category. However, a few stereotypes emerged differently across stakeholder groups. For example, CGs highlighted how birth mother stereotypes affected their decision to disclose their child's adoptive status. As in, some CGs felt they had no choice but to disclose the adoption to avoid judgement; however, they also felt tension about that disclosure, since they may be further stigmatising birth mothers, since the child is theirs no matter the status, and since they should not have to disclose adoptive status to be treated well. HCAPs raised those same concerns, but one HCAP group pointed to birth mother stereotypes impacting even them: several HCAPs providing services to substance-using pregnant women discussed how, given public assumptions about their clients, they chose not to disclose their work (e.g., "[Jokingly] That's why we say we're bingo callers when people ask us what we do" (Jordan, HCAP3)). Finally, two groups of people with FASD, when asked about alcohol and pregnancy stereotypes, had discussions instead about their complicated relationships with and feelings about their birth mothers.

Endorsing some alcohol and pregnancy stereotypes

Most participants identified and rejected demographic stereotypes about women in vulnerable or marginalized situations or communities, calling for more support for these groups instead of increased stigma or blame. However, a CG counter-narrative emerged that rejected those demographic assumptions through the employment of others (i.e., middle- or high-income, white, highly educated, mid-30s). In some cases, this emerged as a concern that demographic stereotypes associated with marginalized groups would cause other women to assume health advice about alcohol and pregnancy was not relevant to them; that FASD "happen[s]" to other people. In other cases, the counter-narrative itself became the stereotyped account.

Stereotypes associated with non-biological caregivers for people with FASD

In Table 3, we describe three categories of stereotypes associated with the non-biological caregivers of people with FASD: (1) Overparenting (i.e., CGs seen as hover parents, who coddle or spoil their children); (2) Bad parents; and (3) Saints (i.e., CGs seen as adopting children with disabilities for the greater good). We did not find content on the impact of CG stereotypes.

Table 3: Stereotypes associated with non-biological caregivers for people with FASD

Caregiver stereotypes	***Illustrative examples of caregiver stereotypes***
Overparenting (i.e., examples that suggest a CG might coddle, protect, or spoil their children inappropriately).	"I was told I was a hover parent… that he had to learn to do this himself, and if I didn't back off, he was never going to make it in university" (Lucinda, CG4).
Bad (i.e., examples that suggest a CG might not be a fit parent)	"It's ignorant stereotypes: 'You're a bad parent. That kid's spoiled rotten that's having a tantrum in the middle of the store'. [My child] cleared a [local store] when she was [very young]. They had to close the store. 'You're a bad parent, and she's a bad child, she's a spoiled child'. So, it's more ignorant stereotypes" (Jennifer, CG3).
Saintly (i.e., examples that suggest CGs are exceptional, in contrast to others who would not have adopted children with disabilities)	"…people tend to say to you 'oh, you're such a saint'… They say to me 'why in the world would you take that on yourself?... Oh, aren't you such a wonderful person'… Especially in church… they think that we are saintly people and I just say: 'I just wanted a family for goodness sakes'. You don't do it out of saving the world, right?" (Nathalie, CG1)

How participants discussed non-biological caregiver stereotypes

This theme emerged in discussions with CGs, since we only asked participants explicitly about FASD, or alcohol and pregnancy, stereotypes:

> When you address stigma, and we talked about stigma of birth mothers and stigma of the person with FASD, I think we also need to address the stigma of adoptive parents because I think we are stigmatized as bad parents, helicopter parents, overprotective… (Emily, CG1).

This topic was not common or detailed.

Discussion

Stigma associated with stereotyping has been identified as a challenge for individuals with FASD across the lifespan and for women who drink while pregnant. This paper, which reported on a portion of the data from a study of the experiences and perspectives of key FASD stakeholders, provides a deeper understanding of the stereotypes faced by people with FASD, their birth mothers, and their caregivers grounded in lived experiences (Tables 1–3 respectively). It also provides insight into Link and Phelan's model, concretising several elements through our participants' experiences and concerns. (For more on operationalisation of theoretical concepts through qualitative inquiry, please see work in pragmatic bioethics by Racine et al. (2019)).

For example, we asked questions about two of five elements of the model: labelling differences and stereotyping. Of course, in asking questions designed with this model in mind, we found ample evidence of related experiences. However, perhaps unexpectedly, we also found participants discussing at least one other element: othering (Link & Phelan, 2001). First, participants suggested that women who drink while pregnant may be perceived as more likely to fit certain demographic categories (e.g., low income), which could allow other women (e.g., high income) to believe that FASD does not happen to them or in their communities; demographic stereotypes may enable some to assume it "can't happen to me" – othering both marginalised women and people with FASD. Here, othering could have the effect of not only marginalising certain groups via stereotyped public understanding and discourse, but it could hinder FASD prevention and help-seeking behaviour (Zizzo & Racine, 2017). Second, CGs explored challenges associated with disclosing their child's adoptive status. In this case, participants were concerned with how their own actions could contribute to othering more marginalised women like their children's birth mothers, to avoid themselves being othered.

In this section, we discuss some implications of participant-reported stereotypes, and how they relate to stigma. First, we reflect on how stereotypes raised by participants relate to or differ from stereotypes identified in media coverage of disability. Second, we explore shifting stereotypes, assumptions, and expectations around alcohol, pregnancy, and women's agency (Link & Phelan, 2001).

FASD stereotypes: Turning the page on narratives of hopeless inevitability

In our study, we identified two categories of FASD stereotypes: stereotyped expectations about (1) the abilities and (2) the life trajectories of people with FASD (See Table 1). In the first case, people with FASD were presented contradictorily as both incapable of success and as too "normal" to be impaired. In the second, people with FASD were associated with negative life trajectories, especially for marginalised groups. Participants felt these stereotypes could have two main effects: they could generate and perpetuate negative attitudes about FASD leading to barriers such as limited support, and to self-fulfilling prophecies. We judged mass media to be one potential source of narratives that could contribute to such attitudes.

Media portrayals of different groups can both inform and reflect a society's values, views, and attitudes (O'Shaughnessy & Stadler, 2008). Consequently, analysis of media content can provide insight into how certain groups have been perceived and represented in mainstream contexts over time (Haller et al., 2012). Previous work has identified a set of common, stereotyped, and potentially harmful portrayals that reflect unnuanced accounts of the lives of disabled people and communities (Barnes, 1992; Haller et al., 2012). In both news and entertainment, those stereotypes include but are not limited to: (1) the victim or object of pity; (2) the hero or object of inspiration; and (3) the villain (Barnes, 1992).

In one previous Canadian FASD media analysis, several stereotypes were found, most prominent being "the villain" through criminal reporting (Aspler et al., 2018). A key difference between that media analysis and the results of our focus groups is that few of our participants pointed to criminal behaviour as an FASD stereotype, unless prompted by media. Evidence of "the villain" appeared instead in more nuanced ways, in stereotyped labels like "a danger" to classmates (Mackenzie, CG1), the "problem child" (Logan, HCAP3), or as just "bad" (participants across all stakeholder groups); however, participants rarely used these examples to evoke explicit concerns around crime – those who did were most often HCAPs. This could be a function of who participated; all participants with FASD had access to support. It is possible that crime would have been raised more often had our sample reflected more of those lived experiences. Nevertheless, it does point to a possibly consequential mismatch between how Canadians with FASD and related stakeholders understand themselves and their life trajectories, and some stereotyped representations offered in print media.

At the same time, stereotyped news narratives associating FASD with crime do share commonalities with one important participant-reported stereotype: that people with FASD are hopeless "write-offs" (Asha, HCAP2) who cannot succeed, even with support. Such stereotypes share the inevitability of expected weaknesses leading to expected negative life trajectories, and they reflect participant concerns about self-fulfilling prophecies. Other scholars have argued that public understanding of FASD begins as a story of "innocent victims" before shifting to one about "undeserving and hopeless" criminal deviants in adulthood (Dej, 2011). While our participants did not often discuss such hopelessness in terms of deviance or crime, they did raise it regarding assumptions about the effectiveness of interventions and supports. They also explored hopelessness through the lens of "permanent" brain damage. As one HCAP explained:

> …messaging went out: "permanent brain injury, this child is broken… [it's] not their fault and there's really nothing you can do about it…" we kind of communicated that… [it's] kind of hopeless… And now we have decided maybe we need to move a little further and say, "you know what, we can get away from blame and we can also get away from hopelessness and we can start to tell a story about different expectations and different successes that are reasonable for the individual"… as opposed to "let's just get this child to adulthood and see if we can keep them from being dead, pregnant, or in jail". (Morgan, HCAP1)

In fact, a narrative of hopelessness has pervaded the FASD literature since FASD was first proposed as a medical diagnosis in the 1970s, when the originators of the diagnosis bleakly concluded that "…the offspring of chronic alcoholic women, whose development and function are often permanently damaged by their adverse intrauterine environment, frequently become a problem for society in postnatal life" (Jones et al., 1974). Armstrong, in her seminal critique of the construction of FASD, argued that such negative attitudes were common among "most of the early writers" where "[b]oth the woman who drinks during pregnancy and her child are [seen as] beyond hope and destined to be societal problems" (Armstrong, 1998). Of course, discourse in medical literature has evolved and improved since the 1970s; however, earlier problematic ways of describing FASD persist and can be seen in the experiences, stereotypes, and hopelessness reported here and in our previous media analysis (Aspler et al., 2018, 2019).

Given such hopelessness across domains, and the felt impact of such hopelessness across social systems, CG concern for their child's future should come as no surprise (Salmon, 2008; Sanders & Buck, 2010; Whitehurst, 2012). People with FASD and their families need more than just support or care into adulthood; they need hope and understanding. They need positive role models with FASD, balanced coverage emphasising weaknesses and strengths together, and professionals across numerous social systems who understand that each person with FASD is unique and can succeed according to their individual capabilities with the appropriate support and accommodations (Flannigan et al., 2018; Morrison et al., 2019).

Agency and alcohol-related stereotypes: Shifting the blame

We identified three categories of alcohol and pregnancy stereotypes: expectations about the (1) demographic profile, (2) behaviour, and (3) character of women who drink while pregnant. In the first case, participants argued that the public sees drinking in pregnancy as a problem largely for marginalised groups. In the second, they discussed stereotyped assumptions about the behaviour of the kind of person who gives birth to a child with FASD (e.g., must be a heavy drinker). In the last case, most participants suggested that these women were viewed as bad people. Participants felt that alcohol and pregnancy stereotypes could have two main effects: stereotypes could (1) contribute to tension for CGs when making difficult decisions about disclosing a child's adoptive status; and (2) lead certain mothers to think that they are not the kind of person who would have a child with FASD.

Many discussions about demographic stereotypes most associated with drinking while pregnant generated a counter-narrative about middle-class mothers. This new set of categories appeared to serve two purposes: (1) to push back against stereotypes that participants had identified as problematic (e.g., low income); and (2) to broaden FASD prevention messaging and public understanding to target all women. This meant that participants often focused discussions about the impact of demographic stereotypes on the behaviours of middle-class mothers, rather than on the negative effects that stereotypes could have on the women they target (e.g., Indigenous women). Ultimately, this shift in focus might also shift culpability away from marginalised women and groups, whose motivations and situations appeared more readily sympathetic to our participants (i.e., drinking due to abuse, poverty, addiction, or as one participant put it: “There’s no excuse for it, but it’s understandable” (Leila, FASD3)) to a group of women who could more easily be cast as villains.

This observation reveals a tension in attitudes about women’s autonomy (Zizzo & Racine, 2017). When women had more resources or advantages, participants saw their choices as freer and the women as increasingly culpable for their drinking (Racine et al., 2017). However, some limited discussion did focus on the possibility that middle-class women could face similar challenges to their more marginalised counterparts (e.g., domestic abuse). Such discussions also raise concerns about the expectations of different groups of women. As highlighted in a previous paper, attitudes about women’s behaviour while pregnant have, in part, been shaped by views about what it means to be a good mother (Aspler et al., 2018). Such a history, at least in North America, has racialised dimensions with poor women of colour, especially Indigenous women, most strongly judged as possible dangers to society (Golden, 2000). While we should remove the burden of stereotypes from marginalised women, this strategy still troublingly assigns blame, providing support and understanding for some while unhelpfully responsibilising others. One potential productive path away from such an individualising discourse could be via community-oriented messages – i.e., discourse promoting partner, community, or family support, rather than targeting mothers as the sole actors responsible for a child's wellbeing (Aspler et al., 2018) – as well as more universalised messaging and education (e.g., teaching children of all genders about FASD, alcohol, and pregnancy in sexual health courses without assigning gendered blame).

Ultimately, a counter-narrative that shifts blame could both help and hinder different groups of women – destigmatising some, stigmatising others, raising attention where needed, but also perhaps driving some of this behaviour further underground. Additional research into the impact of different stereotypes, public health messages, and media narratives on different target populations, and the way related stereotypes are taken up, rejected, or employed in health messaging, could help clarify the use or harm of a shift in this direction.

Limitations

First, we did not conduct interviews with birth mothers or pregnant women who consume(d) alcohol. Despite seeking them out, we did not find any who could participate. However, several participants with FASD were themselves birth mothers of children with FASD. Their views were invaluable in shaping our understanding and the direction of the analysis.

Second, we interviewed people with FASD currently receiving services and support. While these participants reported difficult experiences throughout their lives, support staff still felt that they were sufficiently resilient to participate in this study. Consequently, our participants might have very different life experiences from others without support (e.g., homelessness).

Conclusion

We conducted focus groups exploring lived experiences and media portrayals associated with FASD, alcohol, and pregnancy across three groups: (1) people with FASD; (2) caregivers; and (3) relevant professionals. In this paper, we reported part of that data, identifying three categories of stereotypes and their impact: (1) Stereotypes associated with FASD (e.g., criminal life trajectory, impact: self-fulfilling prophecy); (2) Stereotypes associated with alcohol and pregnancy (e.g., Indigenous, impact: that it *"can't happen to…"* non-Indigenous women); and (3) Stereotypes associated with non-biological caregivers for people with FASD (e.g., overbearing). These results were connected to stereotyped portrayals of FASD, alcohol, and pregnancy in Canadian news coverage and the pervasive hopelessness of FASD discourse broadly, how they reflect social expectations about the agency and behaviour of women and mothers, and how they support the validity and relevance of Link and Phelan's model of stigmatisation in a concrete context. Looking forward, ethical considerations about the kinds of stories and stereotypes that are told and taken up about FASD, alcohol, and pregnancy should be explored further to reduce stigma and enhance the wellbeing of a complex cross section of FASD-connected stakeholders.

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Concluding remarks for chapter 5: Stigma and FASD

The concept of stigma has been central to all three manuscripts so far; Chapters 3 and 4 explored the idea of media content potentially generating or perpetuating stigma (i.e., pitfalls of science reporting, stereotyped stakeholder portrayals), while Chapter 5 provided accounts of or concerns about stereotyping. As discussed, we grounded our work in Link and Phelan's seminal model of stigma, comprised of five co-occurring elements (i.e., labelling, stereotyping, othering, and discrimination in the context of power) [50], with implications for health inequalities [159, 160]. The questions we asked drew on two of five elements: 1) labelling (see Appendix 2, Tables 2-3); and 2) stereotyping (Chapter 5), while also generating unprompted examples of other elements too (i.e., othering). In Chapter 8, I return to this point, to explore how my work could contribute to operationalizing a concept such as stigma in experiential research [119].

Importantly, to specify the concept of stigma, in a recent review, scholars identified four overlapping FASD-related stigmas: 1) public stigma (i.e., "cognitive, affective, and behavioral reactions to a person [perceived] to have a stigmatized condition"); 2) self-stigma; 3) stigma by association; and 4) structural stigma [125]. Each category variously affects people with FASD, caregivers, and birth mothers or women who consume alcohol while pregnant. Notably, the authors found public stigma at the core of the three other categories; it also appeared to be the most commonly discussed stigma, which reflects my work in Chapters 3 and 4. Consequently, while Chapter 5 provides experiential data on public stigma, I want to conclude by pointing to examples of self-stigma and stigma by association that elaborate on and go beyond what was found in Roozen et al.'s review [125]. First, people with FASD reported experiences of and concerns about "self-fulfilling prophecies" – which can be understood as a form of self-stigma – that left some participants feeling they had no option but to behave badly. By internalizing the negative expectations of others, they became the ‘bad’ student or child. Second, some caregivers reported examples of stigma by association. As has also been reported by others [74], the stigma associated with alcohol and pregnancy can lead some adoptive, foster, or kinship caregivers to feel like they have no choice but to disclose their child’s adoptive status to avoid judgement. In some cases, this disclosure ensures that they receive appropriate support or care for them or their child, reflecting how stigma can cause health inequalities [159]. However, moving beyond the example of caregivers, even some professionals reported a felt impact of stigma by association – that they chose not to disclose the nature of their work to others (i.e., social workers supporting substance using pregnant women and mothers) because they were negatively impacted by what they characterized as the ignorant responses of strangers, family, and friends alike. Ultimately, as Roozen et al. explained, more work is needed to understand these other categories of FASD-related stigma – including work to understand how to effectively de-stigmatize FASD [125]. As Choate and Badry argue in another review on FASD and stigma, and as I address in Chapter 6, “stigma will continue unless specific efforts are made to change the discourse” [127].

CHAPTER SIX – STAKEHOLDER REACTIONS TO AND RECOMMENDATIONS FOR NEWS COVERAGE ABOUT FASD, ALCOHOL, AND PREGNANCY

Manuscript IV: Hope, Inclusion, Education, Community, and Fear: Stakeholder recommendations to shift and improve discourse on FASD, alcohol, and pregnancy

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Abstract (250 words)

Background: Media coverage about fetal alcohol spectrum disorder (FASD), alcohol, and pregnancy can include negative, hopeless, and stigmatizing messages about people with FASD and women who drink while pregnant. In this study, we aimed to understand the experiences of key FASD stakeholders and their reactions to news coverage about them.

Methods: We employed a multi-category focus group design to conduct twelve focus groups across three stakeholder categories: 1) people with FASD; 2) their caregivers; and 3) healthcare and allied professionals. We analyzed the data and identified themes using framework analysis.

Results: Participants provided five overlapping and sometimes contradictory recommendations for public and interpersonal discourse about FASD, alcohol, and pregnancy: 1) Hopeful messaging (e.g., strengths-based storytelling); 2) Role modelling and inclusion (e.g., centring the voices of people with FASD); 3) Education and awareness (e.g., teach children about FASD in health class); 4) Community-focused messaging (e.g., include partners in prevention messaging); and 5) Fear-based messaging (e.g., employ stigma in public health messaging).

Conclusions: Participant recommendations about discourse on FASD, alcohol, and pregnancy revealed tension between the needs of different stakeholder groups (i.e., people with FASD versus women who drink while pregnant), messaging tactics (i.e., hope versus fear-based messaging), and messaging goals (i.e., support versus prevention). We explore the public health, medical, and bioethics literatures for efficacy evidence and explorations of the ethics of different discursive tactics. Moving forward, greater attention to lived experience and its complexity is required to appreciate the impact of public messaging about FASD, alcohol, and pregnancy.

Keywords: FASD, stigma, media, communication, alcohol and pregnancy, framework analysis

Introduction

People with fetal alcohol spectrum disorder (FASD), a complex, controversial [1], and heterogenous neurodevelopmental diagnosis resulting from prenatal alcohol exposure [2], can experience stigma, social exclusion, and difficult life trajectories [3-5]. Although such stigma [6] may connect to challenges and stereotypes associated with disability in general [7-9], FASD carries its own unique stereotypes and challenges [10] – specifically, the idea that a diagnosis of FASD is hopeless [11]; that people with FASD are either innocent victims of bad, alcoholic birth mothers or irredeemably deviant criminals incapable of success [12]. Similarly, women who consume alcohol while pregnant can experience stigma, in this case due to the direct connection between alcohol consumption and fetal impairment [13, 14]. Expectations about the roles and behaviours of pregnant women associated with motherhood may also exacerbate related stigma [7]. Notably, commonly communicated ideas about FASD, alcohol, and pregnancy in news media and public health messaging could generate and perpetuate stigma faced by these groups.

In the US, UK, and Australia, media analyses have identified stigmatizing, contradictory, and nuanced coverage on these topics [15-19]. In our previous work, we explored challenges associated with Canadian news coverage of the lives of people FASD and their birth mothers [7], and with science and health coverage about FASD, alcohol, and pregnancy [10]. In addition, we have identified stereotypes of concern to these stakeholders [11]. To address concerns raised by news coverage and stereotypes, we aimed to understand the views of key FASD stakeholders about potentially stigmatizing media [20], and their recommendations to improve public and interpersonal discourse on FASD, alcohol, and pregnancy (grounded in their experiences [21]).

Methods

In this study, we employed a multi-category focus group design [22] to answer questions about participant experiences and reactions to media content, similar to previous work by our group (see [23]). We reported these methods in a previous article about participant experience with and concerns about stereotypes associated with FASD, alcohol, and pregnancy (see [11]), some of which we reproduce here verbatim, or else introduce as specific to this manuscript's focus. The media prompts we showed participants came from our previous media content analysis on FASD, alcohol, and pregnancy in Canadian news [7, 10] (see Appendix 1). Our study design, an interdisciplinary health research approach [24], incorporates theory and methods from bioethics [21], disability studies [9], and sociology [6]. It was approved by the Montreal Clinical Research Institute's research ethics board in accordance with Quebec and Canadian [25] ethics guidelines.

Sampling

Our three stakeholder groups included: 1) adults with FASD (self-identified); 2) caregivers for people with FASD (CGs); and 3) relevant healthcare and allied professionals (HCAPs). We included a range of HCAPs (i.e., physicians, psychologists, social workers, nurses) across diverse domains (i.e., diagnostics, criminal justice, healthcare, addiction, child welfare). We excluded participants who might not understand the questions or who were at greater risk of experiencing distress. We also excluded people who were not proficient in English (discussion prompts came from English-Canadian print news), children, and people not located in Canadian cities to which we could travel and form focus groups.

Recruitment and Participants

We recruited participants through purposive and snowball sampling from several major urban centres across Canada with the help of a national research network (Kids Brain Health

Network (KBHN)) and local support workers [20]. We conducted twelve focus group interviews – four with each stakeholder group – with 4-8 participants each. Sixty-three people participated: nineteen adults with FASD, twenty CGs, and twenty-three HCAPs, and we also conducted a one-on-one interview with a biological father who did not fit other categories. Notably, beyond several participants with FASD who themselves were mothers of children with FASD, we were unable to recruit birth mothers; CG participants were all adoptive, foster, or kinship caregivers.

Participant confidentiality

Before each focus group, participants were asked to sign a confidentiality form. We also coded participant identities. Only the authors and transcriptionist had access to audio recordings and deidentified documents. We attribute quotes using pseudonyms and categories (i.e., Emily, CG) and the specific focus group within their stakeholder category (i.e., CG1 through CG4)

Participant demographics

Most participants (52/63) were women (82.5%): 21/23 HCAPs (91.3%), 17/21 CGs (81%), and 14/19 people with FASD (73.7%). The two male HCAPs were the only physicians who participated. The remaining female HCAPs were nurses (n=1), service-oriented researchers (n=2), psychologists (n=3), and social workers (n=15). We interviewed participants in four major Canadian urban centres across two Canadian provinces.

Semi-structured focus group interviews

Focus group interviews were conducted in English, audio-recorded, and transcribed verbatim by a professional transcriptionist. The first author (JA) moderated the discussions while the second author (AB) took notes. AB was also available in her professional capacity as a social worker if support needs arose during interviews.

Interview Script and Questions

JA designed the interview with the assistance of ER based on Link and Phelan's model of stigma [6] and the results of our media analysis [7, 10]. We adjusted the script, questions, and media prompts based on feedback from FASD scholars and professionals from KBHN, as well as key stakeholders including CGs and adults with FASD (see [20] for more details).

We asked participants four categories of questions, adjusted based on the stakeholder group, on: 1) their lived experiences of FASD, alcohol, and pregnancy; 2) their experiences with diagnosis; 3) stereotypes about people with FASD and birth mothers; and 4) how they felt about certain media prompts [7, 10]. We also asked a cooldown question about what other kinds of stories participants would like to see about FASD, alcohol, and pregnancy, with a focus on positive portrayals. In this paper, we report participant recommendations to adjust, improve, or maintain current public and interpersonal discourse about FASD, alcohol, and pregnancy.

Media Prompts and Participant Reactions

In the last portion of the interview, we presented participants with twenty-three media prompts (see Appendix 1) – from our previous media content analysis – using a projector and PowerPoint. We divided quotes across two categories of themes on: 1) FASD (i.e., prevention, strengths and weaknesses, criminal behaviour, and Indigenous peoples); and 2) women who consume alcohol while pregnant or birth mothers (i.e., alcohol consumption, who drinks, reasons for drinking, and discussions about punishment and consequences). As we explained to participants, we chose quotes that spanned a wide range of perspectives, some more extreme than others, with the aim of sharing content illustrative of a spectrum of opinions – which did not always reflect the most common ways of talking about FASD, alcohol, and pregnancy.

First, we asked participants about their experience with FASD, alcohol, and media in general. Second, we showed participants the media prompts and asked them to focus on several key dimensions – i.e., what did they like or dislike about a prompt, which words would they keep or replace, and whether any additional context could improve a given prompt. Third, we asked them for their recommendations to improve public and interpersonal discourse about FASD, alcohol, and pregnancy based on their discussions. Here, we report participant recommendations, drawing on discussions from across the entire interview, including in response to specific quotes.

Interview Analysis

Developed by Ritchie and Spencer [26], framework analysis includes five steps [24]: 1) data *familiarization*; 2) *thematic analysis* for coding framework development; 3) *indexing,* a systematic application of the framework to the sample); 4) *charting* summarized data into tables to compare between and within participants across themes; and 5) *mapping and interpretation* a visual exploration of relationships between themes. One coder (JA) *familiarized* himself with the data by listening to and reading each transcript multiple times, and by recording voice memos. Two coders (JA, AB) then annotated six transcripts separately (two from each stakeholder group), identifying emerging themes for a *coding framework*. After each transcript, the two coders discussed the emerging framework and a third coder (ER) then reviewed transcripts, assessing the themes developed by the first two coders, providing feedback and resolving disagreements. JA then *indexed* the final seven transcripts (six focus groups and the single one-on-one interview) alone in MaxQDA, returning to the other coders to discuss new or emergent themes and to resolve issues as needed. The final indexed data was reviewed at the end by ER. Finally, JA *charted* the data by exporting and rearranging the MaxQDA data in Microsoft Excel, which was also used to *map and interpret* the results across different groups.

Results

Participants provided five overlapping recommendations to improve public and interpersonal discourse about FASD, alcohol, and pregnancy: 1) Hopeful messaging; 2) Role modelling and inclusion; 3) Public education and awareness; 4) Community-focused messaging; and 5) Fear-based messaging (see Table 1). First, we describe those five recommendations with illustrative examples. Second, we explore which stakeholders provided which recommendations, when relevant, and similarities or differences in how those recommendations were proposed. Finally, we reflect on overlap and tension between recommendations, recognizing that some may be mutually exclusive or contradictory. We also explore how each of these recommendations was applied (or was not applied) to either people with FASD or women who drink alcohol while pregnant. Most direct responses occurred after participants were asked A) to reflect on specific media prompts; or B) about the kinds of stories they want to see in the future.[1] However, these recommendations also reflect their discussions, consensus, and disagreement in aggregate. While this manuscript emphasizes reactions to public discourse, participants also used these prompts to explore interpersonal discourse – between doctors and patients, between parents, etc.

Table 1: Participant recommendations to improve public and interpersonal discourse about FASD, alcohol, and pregnancy

Participant Recommendations	Illustrative Examples of Recommendations
Hopeful messaging: Participants wanted more success stories (balancing challenges with accomplishments) and less negative or hopeless language	“[We should communicate] the fact that kids with FASD can succeed if they get the support that will help them. They can go to college; some even go to university with support and can hold a job…” (Nathalie, CG1). “If you listen to parents and caregivers, one of the things that strikes them… and maybe for all of us [HCAPs] that go through the training… there can be a message of

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[1] Although we explicitly asked participants at the end of the interview about strengths, accomplishments, and positive messaging, all focus groups discussed the importance of emphasizing positive dimensions beforehand. However, we did draw on participant responses to this question since these responses were clear and direct.

	hopelessness. These kids… there's just mountains for these people to climb. So, I think the message of hope is just usually critical for people affected by it, but also for caregivers, and also for service providers. We can't give up on them" (Lee, HCAP2).
Role modelling and inclusion: Participants wanted the voices of people with FASD centred in discourse, role models with FASD for people with FASD and their families, and for people with FASD included as part of prevention messaging.	"It makes me want to go and do talking and do what you guys are doing, to go and help. Because we've been in it. We know what it's like… I like helping people" (Leila, FASD3). [In response to media prompts on FASD and criminal behaviour]: "…it's really important in media to hear perspectives of people who are experiencing… whatever they're talking about, right? I think that it's important to get a first-hand perspective because I think it can challenge… stereotypes and the stigma" (Valérie, CG2).
Public education and awareness: Participants recommended broader systemic education initiatives beyond public health messaging – including public awareness campaigns, warning labels on alcohol, and school-based education initiatives for both girls and boys in school health classes.	"…it should be part of health education. We are teaching children about safe sex… it has got to be in schools. It has got to be just part of an everyday conversation" (Mackenzie, CG1).
Community-focused messaging: Participants recommended that public health messaging extend beyond women / mothers alone, including partners, family, friends, and more.	"Maybe something like 'Support your partner… She's not drinking, you don't drink either!'" (Isabella, HCAP4).
Fear-based messaging: Participants recommended women and the public receive fear-based messages both to prevent FASD and to gain further public funding and support for people with FASD, often looking to the use of stigma in health messaging for other issues (e.g., smoking, seatbelts, drunk driving).	"Yeah, could we do something like that, is put a picture of a baby brain on a bottle of alcohol, the same that they do on a package of cigarettes" (Riley, FASD1). [In response to media prompts describing FASD as "life destroying"]: "…maybe that's what we need, you know, for people to really wake up and pay attention to the potentially life destroying consequences of drinking during pregnancy" (Kathleen, CG2).

The first two categories (*Hopeful messaging* and *Role modelling and inclusion*) were most often considered when exploring ways to improve discourse about and for people with FASD; as in, 'hope' and 'inclusion' related most often to ensuring that the voices of people with FASD were heard, supported, and promoted – less often to affected women and mothers, though they were still reflected in some calls for more hopeful and less stigmatizing discourse. The other three categories were most often considered when exploring ways to improve discourse and awareness across society broadly about the impact of alcohol during pregnancy, especially when identifying possible messages and targets for prevention. Additionally, the final category (*Fear-based messaging*) was explored most often in the context of women drinking while pregnant.

Hopeful messaging: "We can't give up on them"

Almost every participant in all stakeholder groups argued that public discourse about FASD, alcohol, and pregnancy needed to be more hopeful. Overall, two overlapping strategies were proposed: 1) more strengths-based storytelling, to balance challenges with successes and positive experiences; and 2) less negative, stigmatizing, and hopeless language.

Strengths-based storytelling suggestions primarily focused on people with FASD (rather than women who consume alcohol while pregnant). Participants wanted to hear about the "accomplishments" and "successes" of people with FASD; they wanted stories that emphasized strengths: "…the things we've done in life that we're proud of … I feel like people only focus on [our] mistakes… but if you focus on [our] accomplishments, you can see how bright and intelligent [we] actually are" (Taylor, FASD1), often balancing strengths against challenges.[2]

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[2] As an example, in 2011, two first-person chapters were published in *Fetal Alcohol Spectrum Disorder: Management and Policy Perspectives of FASD* [27]. In the first, Myles Himmelreich outlined both the challenges he has faced and his strengths, ending hopefully: "Today, I know I'm not just another statistic living with a disability – I'm Myles Himmelreich, a successful young man who has found his ability" [28]. In the second, Charlene Organ also discussed challenging and positive experiences, emphasizing how her supportive relationship with her adoptive

Similarly, in response to negative media prompts, participants argued for the reduction, alteration, or elimination of negative language. For example, prompts describing FASD as a "scourge" or "life-destroying", people with FASD as "victims", or women who drink while pregnant as "doped up druggies" were widely rejected by almost every participant across all stakeholder groups. Participants discussed alternate language suggestions (e.g., "life-altering" instead of "life-destroying"), pointed to quotes they preferred with more positive and hopeful framing (see Appendix 1), and discussed additional context to help improve a given prompt. As participants were discussing certain media prompts, this was the most common recommendation.

Inclusion, role modelling, and prevention: "We take kids like us and speak about it."

Participants proposed that the voices of people with FASD be centred in public and interpersonal discourse about FASD, alcohol, and pregnancy in three contexts: 1) as the subjects of their own stories, discussing their own lives; 2) as role models in support groups for younger people with FASD or for concerned parents; and 3) as part of FASD prevention messaging.

Participants with FASD suggested that they should be the ones speaking in the public sphere about their own lives: "you should let the people who actually have the syndrome speak on it, not the people who are observing us… let the person who actually has it speak before you speak for them" (Taylor, FASD1). The other participants in this focus group all agreed, saying that "they should let us do the media things" (Riley, FASD1) and "I hate when people speak for me" (Jasmine, FASD1). Some participants ultimately hoped that these kinds of stories could help to destigmatize a diagnosis like FASD, looking toward a future in which they could feel comfortable and even proud to tell others about who they are: "it'd be nice for me to go out into

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mother enables her successes, ending hopefully as well: her mother "wants the rest of the world to know that I am special and will show the world that, with love and understanding, anything can be accomplished" [29].

the world and say… 'Yeah, I'm different, and I'm proud to be different'" (Summer, FASD4). CGs and HCAPs also occasionally suggested inclusion, but not as often as adults with FASD.

Participants across all stakeholder groups also pointed to the need for role modelling – in both the stories being told in the public sphere and in private settings – as a means of inclusion that actively promotes hope. For example, one adult with FASD told the group: "I'm part of a support group for parents… I'm there because… I have FAS. A lot of them, honestly, are giving up on their children… And by showing them us, that we've come out of it, that we've made something, it gives them hope… and then they [can] just see it, and they say, 'Oh, if [they] can do it, then probably my [child] can do it, too'" (Riley, FASD1).

However, another important dimension of being able to tell their own stories was for the sake of FASD prevention: "we use the people who have it as a defense to prevent this problem" (Taylor, FASD1). Instead of focusing on how positive stories about the lives of people with FASD could provide hope, role models, or a path toward broader social inclusion, participants suggested that telling their stories and moving away from impersonal "statistics" could help the public to understand the direct negative impact of alcohol use during pregnancy on them.

Public education and awareness: "We have to educate people"

Participants across all groups recommended that the public and certain audiences be educated about or made aware of the connection between FASD, alcohol, and pregnancy. Three modes of education and awareness-raising were proposed: 1) teaching all children of all genders about FASD in sexual health class; 2) raising awareness, including through health campaigns and warning labels on alcohol; and 3) changing the language to better explain the reality of FASD.

Calls for changes to health curricula and more universal approaches to education about FASD, alcohol, and pregnancy arose primarily in discussions with caregivers and professionals:

"Why isn't it a part of sex education?" (Nathalie, CG1) or "I think we should be putting this in health classes in the younger ones… talk about FASD. Talk about pregnancy… how you're going to affect a baby. If you're a boy or a girl, it doesn't matter" (Shirley, HCAP2). In every instance, this kind of discussion focused on systemic changes, starting young, and ensuring it does not only target on girls. These discussions were less about FASD itself and more about alcohol and pregnancy.

In the case of campaigns and warning labels, many modes of communicating the risk of alcohol during pregnancy were proposed, from public health campaigns to labels and warning signs on alcohol or at bars and restaurants: "So now you have the labels on the packages – 'Tobacco causes harm'. What about label on your bottle of wine?" (Isabella, HCAP4). Some participants articulated a need to get the conversation started: "people have to talk about this… get the conversation going" (Mathilde, CG1), since "no one is talking about it" (Dakota, CG1).

Overlapping with the need to eliminate hopeless and stigmatizing language, participants also pointed to language they personally found helpful in helping others to understand FASD: "You've got to change the words, the vocabulary. So we just say he has a *brain injury* and it's like hockey players who get a concussion. That, everybody gets. Now they are talking about concussions and they understand that these guys get concussions, there are very bizarre aftereffects, we just say he's got a permanent brain injury and you can't see it, but it causes him to do strange things that maybe you would never have guessed" (Valérie, CG2). In these cases, participants focused specifically on raising understanding for people with FASD.

Community-focused messaging: "It's the supportive social world"

A few participants (caregivers and professionals) recommended that prevention messaging should not target women alone, but should expand to partners, family, friends, and communities. For example, to ensure “it doesn’t just come down to one person” (Samantha, HCAP4) by “promoting [that] partners also have a role to play” (Emily, CG1). This overlapped with calls for improved universal education, so boys and girls would both learn about this topic in health class. However, while this recommendation mostly focused on the idea of broadening the target audience of health messaging to include communities in prevention processes – arguing “it really does take a village” (Patricia, CG4) – sometimes, participants argued that a father’s alcohol consumption could contribute negatively to a child’s neurodevelopment. As in, beyond being concerned about the social dimensions of prevention messaging, asking communities to support the pregnant women in their lives, some participants argued that paternal alcohol use could be biologically connected to developmental outcomes of children as well.

Fear-based messaging: “Scared is good”

In contrast to the above suggestions, participants in all stakeholder groups argued in favour of using fear and stigma in discourse and public health. This was often reflected in calls to scare potential mothers to ensure they not drink while pregnant: “Scare them!” (Taylor, FASD1). Participants often justified this recommendation through explicit comparisons to the utility or efficacy of stigma in other health campaigns: “…fear is a huge motivator for folks. I mean, quitting smoking, look at the not drinking and driving, I mean how successful that campaign has been because it’s a fear-based campaign, right?” (Lee, HCAP2). Discussions about scaring women (or the public) sometimes directly contradicted participants’ previous reflections, where most called for support and empathy for pregnant women. When asked about this contradiction, participants often qualified the call for the use of fear: “Well if I said maybe they need to be scared, that wasn’t how I meant it to come across… I think the statement was something about if you talk about drinking in pregnancy, it might scare them. And I meant that it's okay to scare them in that way if it prevents them from drinking as part of pregnancy" (Isabella, HCAP4).

While fear was almost entirely recommended when targeting the public or relevant women, one CG also suggested fear might help people with FASD: "…sometimes, these things put to them will maybe help them realize that they need a certain amount of support to get through everyday life, or to seek the support that they may need because they each aren't going to need the same support system" (Amaya, CG2). However, most participants, including a few who supported fear-based messaging for prevention, raised concerns about the negative impact on people with FASD: "I know if my [child] read that, [they] would be in tears" (Valérie, CG2).

Hope or fear: Tension among participants and their recommendations

An explicit debate that arose, most often among caregivers and professionals, explored whether to promote and propagate hopeful or more fear-based messaging. This tension emerged, implicitly and explicitly, when considering target audiences – while most participants agreed that hope mattered for messaging about FASD, alcohol, and pregnancy, they also disagreed about the utility of hopeful messaging when considering FASD prevention targeted at either the broader public or at-risk women. For example, one quote that prompted discussion about the utility of hope was: "Fetal alcohol syndrome is an entirely preventable, potentially life-destroying disability." Most participants disliked the language of "entirely preventable" (e.g., "It is entirely preventable should no woman drink while she is pregnant, right? But that is kind of a huge thing to ask… while there is violence in families, while there are addictions, while there is no supports… it puts a whole lot of pressure on a very small percentage of people" (Elisapie, CG2)) as well as "life-destroying" (e.g., "Having a disability isn't life destroying, right? And when we put that across the lifespan of like what disabilities are… it's ableism" (Dominique, HCAP3)).

However, some participants preferred this language, either because they felt it was useful for prevention or else that it was accurate and therefore appropriate. In one group of CGs, when some participants argued that the quote was too negative and promoted hopelessness (e.g., “It’s like somebody’s put the stamp down. They’re done. There’s no help” (Maya, CG3)), another responded that hopeless messaging like this could be useful when considering how to garner public support: “…we don’t get the supports unless we tell it like it is… I say, we say what happens if you don’t get the supports… It is exactly potentially life-destroying…” (Jennifer, CG3). This CG argued that awareness, appropriate health choices, and support could be attained through fear-based messages, by evoking other examples of stigma-based public health discourse (e.g., smoking, drunk driving); by scaring the public, people would act to prevent FASD and help people with the diagnosis: “…maybe that’s what we need for people to really wake up and pay attention to the potentially life destroying consequences of drinking during pregnancy”.

In response, other CGs pushed back, arguing that “you’re also not going to get supports if you have a diagnosis that says their life’s already destroyed… Why would we waste our money and resources when there is no hope?” (Maya, CG3). In one final exchange, the CG in support of fear argued: “People didn’t stop smoking until they were told it could kill them, okay? It’s accurate” (Jennifer, CG3), with another pushing back that “People still smoke” (Paloma, CG3). This group did not reach a consensus – the participants fundamentally disagreed about the need for hopeful versus fear-based messaging – and, eventually, we changed the subject.

In some other groups, participants explored the difficult and delicate balance between hopeful, balanced, complex, and fear-based coverage: “I think you also have to give hope. There’s got to be a way that you can say that ‘this is dangerous. This is scary, and this is going to hurt your baby; but there’s hope. If you give them the right resources, this child will grow up, maybe not like other children, but he will be okay'" (Shirley, HCAP2). In similar contexts, participants explored maternal blame and responsibility: "I think to an extent you shouldn't blame someone, but then again, they did do it. So, they have to be held responsible…my mum didn't ruin my life. I've done this, I've went to college, I've accomplished so many things… I wouldn't blame her, but I would hold her responsible" (Taylor, FASD1). Different audiences were imagined as differentially targeted by the stigma of these messages – people with FASD, women who consume alcohol while pregnant, the public broadly, adoptive or foster caregivers, etc. For example, though most participants arguing in favour of fear-based messaging focused on its use in prevention with the public and certain groups of women, many participants, in seeing such prompts, concluded instead: "The way that is written, it's no wonder that women who have been drinking during their pregnancy, maybe prior to knowing they are pregnant even, are afraid to come forward to say that they were when things like that are being written" (Amaya, CG2).

Discussion

Stigma and experiences of discrimination have been identified as ongoing challenges for both people with FASD and for women who consume alcohol while pregnant [3-5, 13, 30-32]. While there are many potential sources, targets, and consequences of stigma [6, 33], our work has previously explored the possible role of news coverage in its generation and perpetuation [7, 10, 11]. Consequently, to further understand the potential impact of such coverage on key FASD stakeholders, we conducted focus groups to understand stakeholder reactions to Canadian news. In this paper, which reports on a portion of the focus group data, we identified five overlapping participant recommendations to improve public and interpersonal discourse on FASD, alcohol, and pregnancy: 1) Hopeful messaging; 2) Role modelling and inclusion; 3) Public education and awareness; 4) Community-focused messaging; and 5) Fear-based messaging. Several of these recommendations reveal a tension between messaging goals (i.e., prevention or support), targets (i.e., the public, people with FASD, certain groups of women), and methods (i.e., fear or hope). Recognizing a diversity of opinion, the mutual exclusivity of some suggestions, and difficulty in building consensus around complex and sensitive topics, we draw on public health, medical, and bioethics literatures to explore both the efficacy and ethics of these recommendations.

Improving education and awareness through community-focused messaging

Participants often recommended formal education programs and awareness campaigns as methods to improve discourse. These recommendations often focused on the public broadly (including children in school), specific groups (e.g., doctors, journalists), or broader social circles (e.g., partners, friends). Here, we consider the efficacy and ethics of a common recommendation – alcohol warning labels – and move beyond social circle- and community-focused messaging to explore Indigenous community-led programming. We also explore medical literature about the potential impact of a male partner's alcohol consumption on developmental outcomes.

Alcohol warning labels and similar methods of education and raising awareness were commonly supported and recommended by study participants. However, as Thomas et al. found in a 2014 review, "while [alcohol warning labels] are popular with the public, their effectiveness for changing drinking behavior is limited" [34]; the evidence does not suggest that these labels alone are effective tools for FASD prevention. At best, the evidence is weak or mixed and more research is required [35], possibly to explore different alcohol warning labels than those used currently [36]. Importantly, beyond their inefficacy, their widespread implementation and adoption raises ethical concerns about their potential harm. Uncritical employment of alcohol warning labels that focus on individual responsibility and do not attend to social determinants of health may unintentionally increase the blame women face for alcohol use during pregnancy

[30], which could make it more difficult for substance using women to reach out for help [14]. Thus, it may be prudent to postpone such a recommendation until more evidence emerges.

In contrast, one growing body of evidence that shows promise for FASD prevention – and that supports the recommendation to promote community-focused messaging – comes from Indigenous communities with trauma-informed and culturally-responsive prevention programs [37]. FASD and substance use have often been uncritically connected to Indigenous peoples without acknowledging histories of racism and colonialism [10], likely over-emphasising FASD while ignoring other diagnoses [38]. In addition, FASD has historically been constructed as a racialized diagnosis assumed to primarily affect poor and marginalized women of colour [10, 15]. In recent years, innovative work in these communities has begun to demonstrate the efficacy of community-focused and community-led prevention efforts in Canada [39, 40] and other countries with histories of colonialism (e.g., Australia [41]). While the evidence comes from a specific context, it supports and ties together several participant recommendations: *community-focused messaging*, *inclusion* (community-led), and *education*.

A final reason why some participants supported community-focused messaging, especially when extended to partners, was the claim that a father's alcohol consumption during conception could contribute to negative developmental outcomes. While evidence does suggest that a father's substance use could potentially influence their partner's choice to drink [42], less is known about the biological impact of paternal alcohol use on developmental outcomes. A lot of the existing evidence demonstrating developmental impairment comes from studies in mice [43], and while alcohol may change semen parameters such as volume and morphology [44], not enough is known about the outcomes of those changes to identify the effects in humans. Still, some have suggested that health advice to avoid alcohol should extend to male partners given their potential genetic and epigenetic contributions to neurodevelopmental impairment [45]. While a father's alcohol consumption cannot cause FASD, since the necessary factor is alcohol exposure in the womb, this could be one area for continued research when considering the importance of community-focused messaging. However, although expanding health messaging beyond mothers could help destigmatize certain marginalized groups [11], it could nevertheless also perpetuate stigma by targeting additional marginalized groups (e.g., Indigenous men).

The efficacy and ethics of fear versus hope: Stigma in public health messaging

Link and Phelan's seminal model of stigma describes a process of stigmatization via five co-occurring elements: 1) labelling difference; 2) stereotyping; 3) othering; 4) discrimination; in a context where 5) power is wielded against marginalized groups [6]. Many have applied this model in the context of health conditions [33], arguing that stigma is a "fundamental cause of health inequalities" [46]. Health campaigns and messaging that employ stigma can typically be tied to appeals to fear, grounded in "the assumption that by vividly demonstrating negative and life-endangering consequences of risk behaviors, people will be motivated to reduce their current risk behavior and adopt safer alternative behaviors" [47]. It is with these concerns in mind that we explore the efficacy and ethics of stigma and appeals to fear in public health.

When our participants balanced or raised competing recommendations to promote hope or fear in FASD prevention and to raise support for people with FASD, they often turned to other public health contexts and campaigns that employ appeals to fear for evidence: smoking, drunk driving, seatbelt use, etc. Related health messaging commonly employs appeals to fear [48]. As with alcohol warning labels, fear appeals may intuitively appeal to the public, independently of their efficacy [49]; however, unlike alcohol warning labels, health-based appeals to fear are supported by a stronger body of evidence – including the use of different warning labels in other contexts (e.g., large and graphic anti-smoking images) [50]. Consequently, we cannot simply dismiss fear by raising concerns about unethical or unintended side effects. Of course, bad faith or scientifically unproven appeals to health-related fear – e.g., fear based on false claims associating vaccines with autism [51] – can much more readily be dismissed as unethical [50].

In the literature that explores the evidence, ethics, and side-effects of appeals to fear, limited consensus exists. Some authors claim that fear is effective and has shown no stigma-related side effects [48], others summarize mixed evidence of efficacy that depend on variables like context, message content, and target audience [50], and others still point to possible defensive reactions suggesting that fear may be counterproductive in some cases [52]. Notably, when scholars break down appeals to fear and responses to such appeals into component elements across different theoretical frameworks – e.g., fear arousal (threat severity of a fear-based message) [47], self-efficacy (beliefs about one's ability to respond to a threat), and response efficacy (beliefs that a response will work) [53] – nuance emerges about when fear may be an appropriate tool; the context and target audience are incredibly important. Focusing primarily on threat severity may be the least useful part of appeals to fear; evidence supports the existence of "counterproductive effects of threatening health information with those most at risk (usually those for whom the message was designed) being most likely to reject threatening health information" [47].

Concerns about self-efficacy and counterproductive responses have great relevance to the context of messaging about FASD, alcohol, and pregnancy. Even if widespread appeals to fear to prevent alcohol use during pregnancy were to demonstrate a broad reduction in substance use when pregnant, those most at-risk or most likely to be targets of such a message may be the least likely to respond well – i.e., women in difficult circumstances they feel they cannot change (e.g., addiction, abuse). Importantly, even in groups for whom this messaging may be effective, given that many pregnancies are unplanned and alcohol consumption can happen prior to awareness of a pregnancy, it is unclear whether expansion of warnings to a ‘pre-pregnancy’ period would help, other than to promote blame, shame, and guilt in mothers who stop but were ‘too late’. As Roozen et al. articulate in a recent narrative review, prevention messaging should be “a matter of communicating what pregnant women can do rather than what they should not do” [54].

Finally, a central problem we see in these tensions relates to the possible collateral effects of prevention: Messaging aiming to stigmatize drinking in pregnancy might not only stigmatize certain groups of women, but also people with FASD [10]. While participants argued that we must be more inclusive of and promote hope for people with FASD, some also argued for fear-based prevention messaging aimed at stopping alcohol consumption during pregnancy; however, in scaring women and the public, FASD is likely to be described negatively or hopelessly. This invokes elements of the “expressivist objection” or argument [55], which suggests that it can be difficult to simultaneously express support for people with disabilities while aiming to prevent said disability, which, for some, might be a part of their identity [56]. Given the complexities of distinct messaging goals, targets, tactics, and effects, much greater consideration must be paid to the use of stigma in public health messaging for FASD, alcohol, and pregnancy. Additional research into the efficacy, impact, and ethics of discourse related to FASD is needed.

Limitations

This study has several limitations, which we have reported in full elsewhere, some of which is recalled here [11]. First, we were unable to conduct interviews with birth mothers or pregnant women who consume(d) alcohol; however, several participants with FASD were birth mothers of children with FASD. Second, we interviewed adults with FASD receiving services. While participants reported experiencing challenges, support staff felt they were resilient and could participate. Consequently, they may have different life experiences from those without support.

Conclusion

We employed a multi-category focus group design to better understand experiences and reactions to media coverage associated with FASD, alcohol, and pregnancy across three groups: 1) adults with FASD; 2) caregivers; and 3) healthcare and allied professionals. In this paper, we reported part of that data from a larger study, identifying five overlapping recommendations for how to best communicate information about FASD, alcohol, and pregnancy in both public and private settings. These recommendations were: 1) Hopeful messaging (e.g., “We can’t give up on them”); 2) Role modelling and inclusion (e.g., “We take kids like us and speak about it.”); 3) Public education and awareness (e.g., “We have to educate people”); 4) Community-focused messaging (e.g., “It’s the supportive social world”); and 5) Fear-based messaging (e.g., “Scared is good.”). Recognizing tension between recommendations, needs of different stakeholders (i.e., people with FASD and women who drink while pregnant), messaging goals (e.g., prevention versus support), and the possible counterproductive use of fear in specific target populations, we recommend further exploration of the potential impact and efficacy of different discourse about FASD, alcohol, and pregnancy, to enhance the overall well-being of all FASD stakeholders. We further recommend an exploration of messaging or campaigns to actively de-stigmatize FASD.

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Appendix – Media Prompts

Media prompts about FASD

Slide 1: FASD – Prevention

1. “Fetal alcohol syndrome is an entirely preventable, potentially life-destroying disability”.
2. “It is a promising start to a preventable scourge that has a debilitating, life-long imprint on its victims”.

Slide 2: FASD – Strengths and weaknesses

3. “…everyone said that, because they are mentally challenged, I shouldn't expect them to ever do anything”.
4. “[She] wants to teach people that she and others like her who suffer from [FASD] are not stupid”.
5. “But it's often an invisible brain injury, difficult to diagnose and masked by articulate speech and regular appearance”.

Slide 3: FASD – Criminal behaviour

6. “FAS… appears to lie at the root of much of the senseless crime and sexual deviance that confounds society”.
7. “A well-respected American study found 60 per cent of kids with FASD had been in trouble with the law”.
8. “No one should label everyone with FASD as potential criminals or dupes eager to be recruited by gangs”.

Slide 4: FASD – Criminal behaviour (continued)

9. “Because of their neurological development, they can't distinguish between right and wrong”.

10. “I got locked up again... I never blamed it on [FASD], I knew right from wrong and knew what would happen if I broke the law and got caught”.

Slide 5: FASD – Indigenous peoples

11. “FASD is most common among Canada's native peoples”
12. “FASD is widely seen as an ‘aboriginal problem.’ It is not”.

Media prompts about alcohol and pregnancy

Slide 6: Women who drink while pregnant – Alcohol consumption

1. “…no one knows what amount of alcohol during pregnancy is safe. That's why Health Canada… recommend[s] that the most prudent choice for women who are pregnant is to abstain from alcohol”.
2. “[She] said clear messages are key so expectant mothers aren’t confused. But she did raise concerns... ‘Some women drink before they know they’re pregnant... I wouldn’t want them to get… scared’.”
3. “But every drink is like a spin of the revolver in a game of Russian roulette: It may do no harm, but then again, it might”.

Slide 7: Women who drink while pregnant – Who drinks?

4. “She thought many people believe the mother of a fetal-alcohol child drinks out of a brown paper bag and falls down drunk all the time”.
5. “…25 per cent of all women with children under 5 reported drinking alcohol while expecting babies. But among higher-income mothers, it was 29 per cent, while only 21 per cent of poorer women reported doing so”.

Slide 8: Women who drink while pregnant – Reasons for drinking

6. “I've never encountered any woman who has set out to intentionally harm her child… These women use [alcohol] as a way of coping with… extremely difficult circumstances”.
7. “To get a buzz, to lower inhibitions, to forget problems”.
8. “Plenty of expectant mothers are exposing their fetuses to alcohol… before discovering they are pregnant”.

Slide 8: Women who drink while pregnant – Consequences and punishment

9. “I think pregnant women found drinking in this country should be arrested and charged”.
10. “Punishing these women is not helpful, it stigmatizes and shames them, which keeps them from reaching out for support”.
11. “These doped-up druggies should be sterilized”.

Concluding remarks for Chapter 6: Experiential FASD data and normative conclusions

In this paper, we explored participant-proposed recommendations to shift or improve public and interpersonal discourse on FASD, alcohol, and pregnancy. As explored in Chapter 2, by employing an integrative pragmatist approach to *morally problematic situations*, this paper reflects deliberation about how to act on identified tensions. Implicit in this discussion are two key assumptions: 1) that we should root responses to challenges associated with discourse and stigma in the experiences of affected stakeholders; and 2) that such responses can and should be rigorously assessed or tested. While such assumptions may appear opposed – and tension does exist – they act as important checks and balances that enable us to employ descriptive and experiential data in support of normative conclusions. Such assumptions safeguard ethics from becoming a fixed, unchanging form of morality [119, 161]. Like Whitehurst in a study of the experiences of FASD caregivers, I "did not aim to consider whether or not this is the *truth* for all [FASD stakeholders], but generated concepts that may provide a framework for considering the issues faced by [those stakeholders]" [74]. Participants may or may not be correct, but their deliberation and *prescriptions* can help guide our assessment of how to proceed. As discussed in Chapter 2, the idea of epistemic injustice can provide an important justification for ensuring that we understand complex *situations* [120] through the lenses [162] of a variety of actors and theories [48]. Ultimately, it is not controversial to claim that the facts at hand – that the details of a given context or situation – could or should inform moral reasoning about various ethical challenges. What remains contentious is the way *is* might inform *ought*; as in, how empirical and experiential data can be meaningfully incorporated into ethics theory [119]. Although I explore and expand on this idea in Chapter 8 (the thesis discussion and conclusion), my work does not aim to provide a full philosophical account of how to reconcile such concerns.

CHAPTER SEVEN – A REFLEXIVE CHAPTER ON THE ETHICS AND EXPERIENCE OF WORKING WITH ADULTS WITH FASD AS RESEARCH PARTICIPANTS

Volume chapter: Making research more ethical for adults with FASD: A story of stakeholder engagement, accommodation, and inclusion

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Abstract: In this chapter, I discuss my experience conducting focus group interviews with adults with fetal alcohol spectrum disorder (FASD) – a complex neurodevelopmental disability caused by alcohol exposure in utero. Given the heterogeneity of this disability, people with FASD have different strengths and weaknesses. Therefore, for effective and ethical research inclusion, each person with FASD may need unique accommodations, which can help to both minimize concerns about unjust research exclusion and mitigate sources of vulnerability. To explore these issues, first, I describe FASD and the study conducted by the research team. Second, I outline anticipated challenges and risks we aimed to address. Third, I explore key stakeholder feedback critiquing our study protocol and proposed accommodations. Fourth, I discuss several remaining ethical tensions after we adjusted, since new challenges arose in resolving previous ones. Finally, I reflect on the importance of researchers being open to criticism, and working through their moral discomfort.

Keywords: Fetal alcohol spectrum disorder; FASD; justice; research ethics; inclusion; accommodation; stakeholder feedback; focus groups; qualitative research.

Part 1: Introduction

The first time I spoke with stakeholders about my thesis project, I received complimentary critiques. My supervisor and I sought feedback from researchers, clinicians, and parents of people with fetal alcohol spectrum disorder (FASD) – a complex neurodevelopmental disability caused by prenatal alcohol exposure. We listened to their concerns, took them seriously, and made the adjustments. I felt good about being inclusive and open to criticism. Which is why, months later, I worried and stressed after a difficult phone call with other key stakeholders. The call had been both instructive and upsetting; the people I spoke with had taken great pains to review my focus group study materials, concluding that they needed to be reworked. This feedback came from several adults with FASD, a group we had not – but should have – included in the design stage. As a student new to qualitative research, I now worried about the inclusiveness and emotional safety of my study. I also stressed about my personal goals and timelines. I thought I had been doing a good job, but negative feedback, especially from people you hope your work will help, can be difficult – though necessary – to sit with and work through.

Their criticism included three points:

1) Given that we were conducting focus groups, they felt that our script and interview questions were too abstract for some individuals with FASD to understand – including our consent form;
2) They suggested that some media content was too negative and potentially triggering;
3) Most importantly, since our ability to support participants was limited post-study and geographically-restricted, we could not provide adequate mental health services to those who experienced emotional distress later on. They also described our list of resources as not geographically specific enough, and as too focused on children rather than adults.

These were all problems we had anticipated and thought we had already addressed.

In this chapter, I reflect on some of the challenges I experienced in designing and executing a safe and inclusive group interview study for people with “cognitive impairments.” First, I describe what FASD entails, and then explain our research project and its goals. Second, I outline anticipated sources of participant vulnerability and how we initially planned to mitigate them. Third, I explore the above stakeholder feedback, as well as the adjustments we made in response. Fourth I discuss several key research ethics and methodological tensions that arose in the process of resolving previous challenges. Finally, I reflect on the experience of seeking stakeholder feedback, exploring the necessity of such input, as well as the difficulty and importance of remaining open and vulnerable to critique as a researcher. While other chapters in this book defend or justify the importance of inclusive research practices, here, I will take their importance as a given and explore their practical realities.

What is FASD?

FASD results from exposure to alcohol in the womb (Chudley et al., 2005; Cook et al., 2016). Individuals with FASD can experience difficulties across a broad range of “brain domains” – including executive function, intellectual disability, motor control, and language, among others. In a small portion of cases (roughly 10%), people with FASD also present with characteristic facial features (Andrew, 2011). In the 1970s, these visible cases were first described as a “fetal alcohol syndrome” (FAS) impacting the children of “chronic alcoholic mothers” (Jones and Smith, 1973) – which soon expanded, controversially, to include a broader spectrum of both children without observable physical features and mothers who were not chronic alcoholics (Armstrong, 1998; Chudley et al., 2005). FASD eventually emerged as an umbrella term for a number of other diagnoses, including FAS, partial FAS, and alcohol-related neurodevelopmental disability (ARND) (Chudley et al., 2005). In most cases, diagnosis requires confirmation that the mother consumed alcohol while pregnant.

In qualitative studies about their lives, people with FASD discuss feelings of difference, social exclusion, difficulty in school, and problems in employment (Salmon and Buetow, 2012; Stade et al., 2011). Given the cause of FASD, women who consume alcohol during pregnancy can also experience stigmatisation, blame, and shame (Salmon, 2008).

Due to the wide range of areas that can be affected by prenatal alcohol exposure, it can be difficult to describe a 'typical case' of FASD. This in turn makes it hard to develop a uniform set of accommodations for people with FASD, which is a helpful reminder that, no matter the project, participants should be recruited and accommodated based on their individual and diverse support needs, strengths, and weaknesses.

Our research projects

The research team conducted two main studies related to FASD. First, we undertook a media content analysis (Macnamara, 2005) using ten top English-language Canadian newspapers to better understand the landscape of information presented to Canadians about FASD, alcohol, and pregnancy (Aspler et al., In press). Second, we used the results of that media analysis to fuel the design of a focus group study in which we interviewed three key FASD stakeholder groups: 1) adults with FASD; 2) their parents or caregivers (mostly adoptive); and 3) healthcare and allied professionals with relevant experience (mostly social workers) (Racine and Aspler, 2018). In this second study, our objectives were to understand the perspectives and lived experiences of people affected by FASD, and to solicit their views about the media content we analyzed. It was in this second study that concerns about participant support arose.

Our group interviews focused on four key areas of discussion: 1) participant experiences with FASD; 2) experience with a potential diagnosis; 3) stereotypes about people with FASD and about women who consume alcohol while pregnant; and 4) participant reactions to specific media examples from our previous media analysis (Aspler et al., In press). The interviews were two hours long, audio recorded, and semi-structured (Morgan and Krueger, 1998). We conducted twelve focus groups of 4-6 participants, four with each category, for a total of sixty-five participants (nineteen of whom had FASD). A few had identities across participant categories (e.g., a social worker who was a parent of someone with FASD, a person with FASD who had a child with FASD), so they chose which group to join based on their personal preferences.

Our project was motivated by the importance of centring the voices of marginalized persons in discussions about their own lives (i.e., instead of leaving 'solutions' to professionals) (Racine et al., 2013), as well as an interest in fostering deliberation around troubling ethical tensions in FASD communication from a multitude of key stakeholder perspectives (Racine, 2016). We aimed for real-world relevant outcomes, aiming to destigmatize and demystify the lives of people with FASD and their birth mothers. Most previous qualitative research about FASD had focused on the experiences of adoptive or foster caregivers, with very few studies taking the time to talk to people with FASD themselves (Domeij et al., 2018). Consequently, we wanted to turn our attention to those missing central voices.

Part 2: Anticipated challenges for participant inclusion

We knew that some people with FASD may struggle to understand complex informed consent documents, interview questions, and study instructions. Consequently, our original protocol called for the recruitment of people with ARND – a supposedly 'milder' form of FASD. We would still screen participants individually (e.g., by email, phone, recruitment survey) and discuss the consent document in detail (one-on-one and as a group before the interview), but the common framing of ARND as ‘milder’ enabled us to sidestep more serious issues of competence to consent by removing people with other FASDs like fetal alcohol syndrome (FAS).[1] This very quickly proved to be an untenable recruitment strategy for several practical reasons, as well as a clearly troubling approach to certain responsibilities surrounding the principle of justice in research ethics (Canadian Institutes of Health Research et al., 2014; Lai et al., 2006).[2]

First, around the time we finished designing the focus group study, updated Canadian diagnostic guidelines changed existing diagnostic categories from FAS and ARND to FASD with or without sentinel facial features (Cook et al., 2016). In this way, the spectrum became a key part of the diagnostic label, instead of a broad umbrella term encompassing other diagnoses; the idea of a spectrum of alcohol effects had been radically reimagined. This aligns with reconfigurations in the way we think about other spectrum disorders, like autism – i.e., what does it mean to be ‘high functioning’ versus ‘low-functioning’, to use outdated terminology, when individuals have strengths and weaknesses across multiple axes (Happe and Ronald, 2008). For example, when trying to position someone who can cook and clean independently on the spectrum, but who has a low IQ, where would they fall in comparison to someone with the exact

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[1] Given FASD’s expansion over time from physical difference with brain effects to subtler cognitive differences, FAS has often been positioned at the more ‘severe’ end of a linear spectrum. However, FASD is more heterogenous and complex than that. At this stage of my work, having read many news and medical articles continuing to frame ARND as ‘milder,’ I mistakenly built the study around this assumption. And yet, this nuance had been known since at least the mid-1990s. As I learned more about FASD, and as I discuss further down, we later corrected this error.

[2] The principle of justice includes the notion of equity, which means ensuring that the benefits and burdens of research are distributed among appropriate segments of the population. Sometimes, in protecting potentially vulnerable groups from undue burdens, researchers and REB members neglect to distribute benefits of knowledge equitably; they exclude difficult-to-include groups for both practical and ethical reasons. This makes sense when concerned with participant welfare and protection, but can mean leaning too far away from inclusion (Martino and Schormans, 2018). Since our project focuses on the voices of often-excluded groups with “cognitive impairments”, we had to include them. As is clear in the TCPS2: “…individuals who lack capacity to decide whether or not to participate in research shall not be inappropriately excluded” (Canadian Institutes of Health Research et al., 2014).

opposite strengths and weaknesses? A linear, one-dimensional understanding of a spectrum of possible challenges hardly seems helpful here.

Second, many potential participants did not have a diagnosis of any FASD (never mind ARND). This kind of participant typically did not have confirmed prenatal alcohol exposure, but otherwise met diagnostic criteria – or else were still on their diagnostic journeys. We concluded that it did not matter much for our study; what mattered most was understanding how people who identified with the diagnostic label (formally or informally) felt about it and about FASD media coverage. And so, we dropped the specific category of ARND and the need for a mandatory diagnosis from our inclusion criteria, relying more heavily on participant self-identification and our team's research expertise and judgement.

We also knew that some of our questions and media content were negative and possibly emotionally distressing. Consequently, we mentioned this negative content and the risk of emotional distress in the informed consent document. We also talked to participants ahead of time about this kind of possibly-distressing content in more depth, to explore with them how they felt, to ensure they could comfortably participate. Importantly, a social worker (who was part of the research team) was always present – ready to assist any participant who found the questions, media quotes, or discussion topics difficult to handle.[3] A weakness that we recognised in our plan was that, as a Montreal-based research team talking to people about English-language news media, we were conducting the study in different cities around the country, meaning we could not provide in-person assistance several days post-interview. To mitigate this problem, we provided both a list of Canadian resources and the social worker's contact information for any

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[3] The social worker was also present for interviews with parents for the same reason. Although we did not think parents overall would have the same support needs for comprehension, the topics being discussed could still have been very emotionally draining for anyone with personal stakes in discussions about FASD.

who wished to contact us later – something we emphasized to participants. Ultimately, only one parent reached out, but to ask for more specific local resources and programs (a gap later identified by the adults with FASD who provided feedback).

Finally, we presented our questions, media coverage, study documents, and plans for accommodating and mitigating vulnerabilities to several clinical and research professionals with expertise in FASD, as well as several parents of people with FASD and other developmental disabilities. We acted on most of their suggestions (e.g., changing complicated language, the addition of a cool-down question about positive experiences or coverage), but recognized that we had not received feedback from any adults with FASD. In not including one of our three key stakeholder groups in early discussions, we missed some potential major problems.

Part 3: Responding to feedback about inclusion

The aforementioned critiques from adults with FASD included: 1) a lack of local support systems once we left a city; 2) concerns about participant resilience in the face of negative media content; and 3) a lack of linguistic clarity related to linguistic abstraction for adults with potential "cognitive impairments". Although we thought having access to our social worker post-study (by email, by skype, etc.) would be sufficient, we were informed that participants might not reach out due to A) a lack of familiarity with this social worker; and B) only processing emotional reactions to negative content several weeks after the study had taken place. Based on these concerns, we formalized several informal practices (e.g., a break halfway through the interview – something we did not provide to parents or professionals) and added new support protocols.

Local support

We wanted our participants to have access to strong local support once we left, since stakeholders had identified this lack of support as the biggest barrier to research inclusion. We decided to recruit through programs that already had readily available support staff with expertise in – and knowledge of – FASD, who would also be familiar to participants. We would provide all of the study tools to these workers beforehand (i.e., the consent form, the questions, the script, and the media quotes), and they would be present during the interviews.

Furthermore, they could assist us with parts of the consent process, by identifying comprehension gaps for specific participants. Some stakeholders suggested some participants might pretend to understand, nodding in agreement so as not to appear confused in front of their peers, even if they did struggle to understand. Consequently, support staff who knew them well could provide more precise insight into these kinds of concerns prior to and during the interviews. They could also help respond to questions (and communicate with me) after the study. In this way, when we left a city, if participants decided not to reach out to us with further questions or about any potential emotional distress, they could instead turn to a familiar face who knew them well, and who knew what could have troubled them during or after the interview.

Negative content

We also worked with local programs and support workers to recruit adults with FASD who the staff felt could best handle more negative content, given concerns about the potential risks and emotional harm to participants. In this way, the support workers who assisted us acted as gatekeepers, to improve protections for participants. Prior to the interview, we would still interact with participants one-on-one as part of our own assessment of capacity to consent (by phone, email, and through the recruitment survey), but we now had an extra layer of protection.

We also began to conduct these interviews with groups who largely knew each other, to enhance their initial comfort levels and to provide peer support throughout and after the interview. Although the staff were absolutely essential (i.e., one participant had to leave the room during an interview, so a support worker followed them out and spoke with them until they felt comfortable enough to return), this peer support was perhaps even more essential. Through very respectful discussions of similar experiences and different emotional reactions, plus a clear sense of solidarity, it became apparent that many of these participants already relied on each other for emotional support. They encouraged each other to share upsetting experiences with the group, and then provided support (e.g., hugs, verbal validation, paper for colouring, stress balls) if the discussion grew too difficult.

Understanding

To enhance understanding, we took two key actions. First, we simplified some of the questions and explanations from our original script. For example, one suggestion was to remove abstract or metaphor-based language – i.e., “And don’t worry, we’ll have plenty of time later in the interview to *dive into the ideas you bring up in more depth*” [emphasis added]. In this example, the notion of ‘diving into’ the conversation was seen as confusing, since we were not diving into a body of water. Second, we worked with local centres to take the time to go through the consent document with participants. This translated into a number of strategies for enhancing comprehension, including asking local centres to print copies of the form for potential participants weeks before our arrival, answering any grammar questions they may have as they go through the form, and facilitating some of the communication we would have from afar as I discussed the study with them. In these ways, we were able to reduce the language level of the interview script and questions (which, despite having been reviewed and approved by several experts and parents, was still seen as too complex by some adults with FASD), and provide stronger local support for understanding before our arrival. Notably, we could not reduce the complexity of the media quotes, as these were taken verbatim from various newspapers around

Canada. Instead, we took extra time during the discussion of these quotes to explain words and phrases as needed. For example, after reading each quote, I would ask participants if anything seemed unfamiliar. In an early interview, the first time someone asked for clarification about the word “scourge”, another participant defined it using pirates (i.e., “the scourge of the sea”). I then used a similar definition in other interviews (and not just for people with FASD).

With these three key suggestions, we were able to enhance both the process of recruitment and participant protections in order to successfully create more comfortable, more ethical, and more inclusive research.

Part 4: New challenges

In changing our practices, new research ethics and methodological problems arose. First, in working closely with local services, we gave up some control over participant recruitment. This raised important questions about the voluntary character of consent, our capacity to assess risks to individual participants, and the informed consent process itself. Second, in conducting interviews with support workers or parents in the room, or in finding participants who knew each other, we may have impacted or inadvertently shaped participant involvement in the discussion (i.e., the kinds of things they felt comfortable talking about) – since group dynamic is central to understanding and analyzing the results of focus group data (Lunt and Livingstone, 1996).

Research ethics challenges

Voluntary and informed consent

Our previous process of recruitment, which included all three stakeholder groups, involved one-on-one communication with prospective participants who themselves got in touch with us based on purposive and snowball recruitment strategies – so it was their choice to reach out to us. Now, we were asking local social service groups across the country to identify and recruit participants in our place by approaching them – making it a more top-down kind of recruitment. We would still, of course, have control over participation; however, it was a control mediated through a gatekeeper, which could at times become complicated. For example, one participant (in filling out our recruitment survey online) provided the email address of one of the local social workers with whom we were working, instead of a way for me to reach out to them directly.[4] Consequently, it became more difficult to speak with participants (both alone and at all), in order to more independently assess their capacity and volition to take part in the study.

The same concerns also applied to risk-benefit assessments – i.e., in working through gatekeepers, we gave up some control over individual risk-benefit analyses (since workers would choose clients to approach based on their clinical judgement about resilience in our stead). At the same time, these workers were in a much better position to make those judgements, knowing their clients far better than we ever could after only a few one-on-one discussions.

Finally, asking local support staff to identify and approach potential research participants raised questions about the impact of trusted authority figures on the voluntary component of consent. Since previous participants (none of whom we knew) had to reach out to us themselves, the researcher-participant power dynamic was less problematic. Ultimately, we were satisfied that everyone taking part in our study wanted to be there (e.g., by talking one-on-one beforehand, following non-verbal cues, reminding participants they could take a break or even stop entirely), but these ethical concerns were specifically introduced by our solutions to making our project more comfortable, more ethical, and more inclusive. In short, by involving local staff in other cities to ensure a more supportive space, different concerns about participant voluntariness arose.

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[4] To resolve this case, I contacted the worker and asked them to pass along my phone number. In the end, the participant called me and we were able to chat for about 15 minutes regarding their worries and concerns.

Methodological challenges

The presence of support workers or parents during the interviews

Prior to the phone call described at the beginning of this chapter, we had already conducted one focus group with adults with FASD. Even at that time, we knew we would have to make participant accommodations; however, these accommodations were spontaneous. They were absolutely vital to the success of this particular interview, but were not part of a formal process or deeply thought through. On the day of this focus group, a few participants were anxious about the study. They each reacted in their own ways: some asked to speak with me alone about what to expect, and so I shared study questions with them prior to their participation – something I had not done for parents or for health and allied professionals. Others had brought items to fidget with.[5] One participant felt anxious enough to request that a parent stay with us throughout the interview. Although the parent did not sit at the table with us, they remained in the room, behind their child, which could have influenced the kinds of stories and experiences members of the focus group were willing to share with me.

At the same time, had I not shared the questions prior to the interview, or allowed the parent to stay, I would have impacted what participants felt comfortable sharing with me anyway. If they did not feel secure throughout the interview, then their discomfort would have influenced the direction of the discussion. In addition, unlike later groups, these participants started as strangers. And yet, through their positive, constructive, and supportive engagement with each other, a sense of community seemed to grow. After the interview, I watched as all the participants exchanged contact information, promising to keep in touch, to keep discussing their

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[5] This was not something we formalized in the protocol; however, all of the centres we later worked with independently provided participants with amazing accommodations we had not considered – not just fidgets (e.g., stress balls, colouring pencils and paper), but also lifts to and from the interviews and even free childcare services.

traumas and successes, and to maintain a circle of support. I do not know if, in the end, they maintained that contact, but I did come away from that particular focus group feeling like we had built exactly the kind of safe and inclusive space we wanted. Still, I recognized that this interview was the best-case scenario, with the later formalization of accommodations helping us prevent the worst. Thankfully, we were able to accommodate this group's needs, so that they could comfortably share their deeply personal challenges (e.g., experience in jail, a struggle to forgive a birth mother), as well as their joys and successes (e.g., graduation, parenthood).

Ultimately, the key piece of feedback from that phone call – that our participant support system was insufficient – had already been somewhat addressed early on (if informally, without explicit articulation in our study protocol). We were already working with a local service provider – though again, without the formal structures in place for later interviews. We had already found ways to help participants feel comfortable, like including a parent in the room (though not support workers). However, I had not yet realised the necessity of always including each of these options and formalizing them in the protocol.

Part V: Conclusion

In this chapter, I explored the importance of including robust accommodations for participants with "cognitive impairments" – in this case, for people with FASD. The final form of our accommodations was borne out of some difficult-to-hear but ultimately necessary input from adults with FASD. It was hard for me as a researcher to receive negative feedback – both in terms of my hopes for success and regarding the wellbeing of my participants. As a researcher in training, my advice to others is to proactively seek out stakeholder feedback even if it takes extra time, take their criticism seriously, build positively on any feedback you receive, and know that it's okay to feel upset – this kind of work can be emotional, intense, and difficult as we foster spaces for participant dialogue and the expression of sensitive experiences and feelings. Their feedback and those feelings, yours and theirs both, can help you push toward inclusion at every stage of research, whatever form that takes based on your project and the population(s) involved.

The research process and the experiences shared in this chapter speak, in my opinion, to the need for greater inclusion of marginalized voices throughout the development of a research project about them, as well as the need for strong local support in the form of familiar faces and support staff. Even if new challenges arise in the process of accommodation (either ethical or methodological), justice in research requires us to create safer environments for purposes of inclusion. Environments where richer dialogue can unfold – dialogue that could not have happened without the kinds of changes we had to make. Although we ran into a number of issues, our research was made better for the support structures we built into the study – both in terms of ensuring participant emotional safety and with regard to the generation of rich and meaningful discussion data. Most importantly, the voices of a group of people who are often excluded from research became central to the way the study unfolded, not just the study findings.

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Concluding remarks for Chapter 7: Experience, intuition, and reflection

So far, I have focused on ethical concerns identified in media content analysis (Chapters 3 and 4) and raised by the accounts and experiences of participants (Chapters 5 and 6). In taking experiential data as a source of morally relevant information – listening to participant intuitions and deliberation as a partial means to address epistemic injustices [48] – we were able to identify *morally problematic situations* [120] associated with the everyday experience [118] of FASD, alcohol, and pregnancy (Chapters 3-5), as well as to begin deliberation on potential approaches and actions to take moving forward (Chapter 6). In contrast, Chapter 7 serves as a personal reflection – taking seriously the experiences of the researcher and my role in contributing to and ameliorating the identified *situation* – leading to two other important conclusions. First, it enabled me to elaborate on our approach to focus group interviews and the challenges we faced when anticipating appropriate accomodations for our participants with FASD. These kinds of detailed reflections could not have been included in the empirical publications produced from our data. Second, it provided an additional source of insight into the ethical issues associated with FASD, alcohol, and pregnancy – namely, the intution and felt tension (perhaps understood or framed in other terms as the moral distress [163]) of the researcher. Such intuitions were initially used to drive anticipated acceptable accomodations, which were then partially rejected by consulted stakeholders. In turn, the content of the stakeholder critiques (and the discomfort, reflection, and moral growth it produced in the researchers) led to a more ethical approach to inclusion that better responded to the *situation* and everyday challenges of our participants.

CHAPTER EIGHT – DISCUSSION AND CONCLUSION

Thesis summary and overview

The narrative arc of my thesis is simple; I wanted to understand public information about FASD, alcohol, and pregnancy in Canadian media and – should some media content be identified as problematic – what stakeholders think we should we do about it. Of course, the reality of this discourse and effective modes of communication are complex. The research and reflections I presented in Chapters 3–7 aim to bring experiential data into conversation with interdisciplinary health ethics considerations about FASD support, awareness, and prevention. To address these concerns, I focused on media that may generate or perpetuate stigma associated with FASD, alcohol, and pregnancy, identifying three objectives: 1) to understand information presented to Canadians in print media on FASD; 2) to learn about lived experiences and views of Canadians with FASD and related stakeholders; and 3) to understand the perspectives of those stakeholders regarding media content about them. The goal that connected these objectives was to identify challenges for and ways to improve the complex *situations* of people with FASD, and others that the diagnostic label may affect (e.g., birth mothers, adoptive parents, Indigenous peoples).

To achieve these objectives, we conducted two research projects: 1) a media content analysis of top Canadian English-language print news from 2002-2015; and 2) a multi-category focus group project that engaged with diverse FASD stakeholder voices (i.e., people with FASD, caregivers, and professionals). The first project enabled us to qualify the information presented by Canadian news – what is said about FASD, alcohol, and pregnancy, and how it is presented (Chapters 3 and 4). The second project enabled us to learn about participant experiences, focused on the felt impact of diagnostic labelling, stereotyping, and media coverage. By exploring these sensitive issues together in a focus group setting, building consensus and solidarity or exploring strong disagreements, participants also provided recommendations to shift or improve public and interpersonal discourse about FASD, alcohol, and pregnancy (Chapters 5, 6, and 7).

In this final section of my thesis, I aim to tie together the literature and theory identified in Chapters 1 and 2 with the manuscripts in Chapters 3-7. First, I explore the tension between the scientific evidence that underpins a diagnosis of FASD – a neurodevelopmental impairment – and the social construction and moralizing discourse influencing public response to FASD, alcohol, and pregnancy. Second, I explore the theory underpinning our operationalization of the concept of stigma, as well as the connection between our experiential data and any potential normative conclusions. Finally, I open the discussion toward new questions and avenues of research suggested by both the work presented in my thesis and the broader FASD literature.

FASD: A diagnosis rooted in scientific evidence, clinical practice, and social values

A diagnosis of FASD exists as a complex combination of biological and physiological impairment and socially constructed disorder. This can be seen in its evolution and expansion over the last five decades, which reflect evidence of the teratogenic effects of alcohol on fetal neurodevelopment [4, 5, 7, 84], fears about the changing role of women in society [14, 24, 25], and assumptions about a hopeless prognosis for a person exposed to alcohol in utero [36, 45, 47]. Developmental outcomes, life trajectories, and which people receive a diagnosis can be informed by clinical and social variables like nutrition, genetics, metabolism, race, poverty, child welfare status, and incarceration [164, 165]. Research also suggests that increased alcohol consumption increases the risk of FASD, but not all children exposed to alcohol have FASD [29]. In terms of a diagnostic process, FASD requires a large multidisciplinary assessment team, is constructed as a diagnosis of exclusion [4, 5], and may be over-diagnosed in Indigenous peoples [123].[13]

Taken together, these overlapping scientific, clinical, and social challenges suggest several mechanisms and pathways by which social values, beliefs, and views could influence clinical judgement and practice, as well as public understanding – where stereotyping and stigma could play significant roles in shaping attitudes about and responses to FASD, alcohol, and pregnancy. Other challenges associated with FASD – from sexism to ableism [46], addiction to colonialism [47], criminal justice to child welfare [167] – similarly reflect controversial and sometimes inflamed discourse, and conflicting ideologies and associated policy solutions. For example, in the case of addiction, some believe it to be a personal moral failing, others, a medical condition or brain disorder, while others still argue that framing addiction as a medical condition stigmatizes substance using individuals, helpfully removing some elements of moral culpability while unhelpfully constructing such a person as dangerous [128, 168-170]. Debates continue about effective and appropriate policies to enact tied to different political ideologies – from the punitive measures of the war on drugs to harm reduction like safe injection sites and drug decriminalization [171]. Ultimately, each of these topics alone could and do inform entire thesis projects and research programs, but the context of FASD, alcohol, and pregnancy invokes them all at once. In part, I do not employ a more traditional model of bioethics in my thesis[14] –

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[13] Some have even argued against applying a diagnosis at all, recommending clinicians focus instead on each child's functional support needs [166]. This suggestion may be supported by the experiences and barriers reported in our media sample (Chapters 3 and 4), focus groups (see Appendix 2), and in the existing experiential literature [57]; as in, stakeholder diagnostic journeys can be fraught, with some reporting unsupportive healthcare and allied professionals and systems, as well as sometimes having to advocate or "fight" for a diagnosis or support alone.

[14] This is of course an oversimplification; bioethics (itself a response to more abstract top-down ethics) constitutes a plethora of methodological and theoretical approaches, from a commonly employed mid-level principlism [172], to bottom-up case-driven casuistry [173], to other modes of ethical deliberation about the relationship among stories, patients, and professionals such as narrative medicine and narrative ethics [174]. Many of these models also take seriously the central role of experiential / empirical data, or at least the stories evinced through their varied methodological approaches – from person- or patient-centred care [175] to whole-person care [176].

turning to feminist and pragmatic bioethics and disability studies – because challenges associated with FASD, alcohol, and pregnancy are broader than clinical decision-making or healthcare systems alone. They evoke group identity and stigma, and how gendered and racialized bodies [15, 38] and othered minds [52, 53] interact with overlapping systems: child welfare, social services, education, healthcare, Indigenous services, and criminal justice, to name just a few.

Systemic responses to systemic problems: Disability activism and the social model

Given the overlap of so many social systems and cultural forces associated with FASD, systemic approaches are required. Disability studies offers several recommendations to address these challenges in the form of the social model of disability, which suggests that disability is not something located in bodies or minds, but in unaccommodating societies [134]. Fundamentally, the solution to disablement (i.e., the active disabling of people by societies) is systemic change – building more inclusive environments (e.g., curb cuts, wheelchair ramps), providing inclusive social services (e.g., independent housing, workplace accommodations), and promoting inclusive public attitudes. Notably, different variants of the social model present different possible sources of disablement and paths forward. One important model, the minority group model [177], points explicitly to the stigmatization of impairment as the main source of social exclusion and "spoiled identity" [122]. According to this model, the solution to exclusion is civil rights protections and anti-discrimination legislation [178]. In Canada there have been attempts to legislate on FASD and criminal justice, but more holistic and cross-system approaches are needed (see Chapter 3).

Neuroscience communication: FASD as permanent brain injury

Concerns about public understanding of neuroscience provide another important lens through which to view challenges associated with FASD as a clinically, scientifically, and socially constructed diagnosis. In an early and seminal neuroethics paper, Racine et al. described three neuroscience communication challenges to avoid: 1) neuroessentialism – an uncritical reduction of self or identity to the brain; 2) neurorealism – how pictures of a brain may "make a phenomenon uncritically real, objective or effective"; and 3) neuropolicy – ideologically-driven use of neuroscience evidence to promote troubling political agendas [106]. A neuroessentialist account of FASD as just a "permanent brain injury" that cannot be "cured" due to prenatal alcohol exposure – reducing a person with FASD to their "alcohol-affected" brain – fails to address how brains can adapt with intervention and how support and accommodation enable success. A neuroessentialist view of FASD reduces all factors to the brain alone, rather than seeing FASD as a complex mix of scientific, clinical, and social factors that can be addressed, supported, and managed. Such views could lead to unhelpful neuropolicy responses that do not address FASD's heterogeneity and the possibility of effective behavioural interventions.

In Chapter 5, participants in all stakeholder groups discussed stereotyped assumptions about FASD stemming from its (in)visibility; as in, others did not always believe that FASD requires accommodation (since these others could not 'see' FASD), instead labelling participants as "lazy" or "stupid".[15] Participants also reported that framing FASD as a "brain injury" rooted in permanent brain damage may promote stereotypes suggesting that people with FASD cannot change, improve, or succeed – even with intervention. Several scholars have highlighted that this promotes a narrative of inevitable negative life trajectories for people with FASD as deviant criminals or substance users [14, 45, 47, 180]. In contrast, as seen in Chapter 6, some caregivers explained that defining FASD as a "brain injury" helped them convince others of the existence and severity of FASD. Neuroethics scholars have long-debated the potential power of brain-

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[15] While FASD can and does present with visible sentinel facial features, these are only a minority of cases [179]; most cases are not visible through any physical features, a major reason why diagnosis can be so complex [29].

based explanations to convince and persuade (i.e., neurorealism) [98-100], which may contribute to FASD being more readily accepted and understood when described as brain damage.

Understanding FASD as a permanent brain injury with no effective interventions has serious real-world implications. In a review of Canadian criminal cases, Chandler found the most common use of neuroscientific evidence in Canadian criminal courts to be an offender's FASD diagnosis – most often when the accused was Indigenous [181]. The use of neuroscientific evidence of FASD and the subsequent treatment of offenders was not always consistent. While FASD was a mitigating factor in some cases (i.e., "the judge noted that it was 'manifestly unfair to make an individual pay for their disability with their freedom'"), it led to harsher sentences in others: "the judge noted that FASD contributed to his behavioral problems and his lack of success in treatment, but considered that there is no cure for FASD and that the protection of the public required incarceration" [181]. This example represents the "double-edged sword" of neuroessentialism and neurorealism; if a person with FASD cannot be held morally responsible for their actions due to a permanent brain injury, then they also cannot be rehabilitated.[16] While alternative placements and measures were also sometimes considered, a lack of placements meant jail was still the only option. This is also an example of where a social model of disability would require funding for alternatives, to ensure that people with FASD can flourish.

Finally, legal cases associated with FASD reported in print media also revealed different ways of understanding FASD-related impairments in moral reasoning. FASD was associated with crime through 1) an inability to connect *consequences* to actions; 2) a lack of understanding of the difference between right and wrong *actions*; and 3) no *intention* to behave criminally, but it resulted in criminal behaviour nonetheless due to impulse control issues. Taken together, our

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[16] This is the same problem described earlier regarding public understanding of and stigma toward mental illness, when mental illness is uncritically reduced to nothing more than uncontrollable brain function [168-170].

data and several previously cited studies suggest that a more comprehensive study of FASD and moral reasoning is needed, bearing in mind the individual and the heterogeneity of FASD.[17] This research question draws on the "neuroscience of ethics," a component of neuroethics, related to the core assumptions of philosophical pragmatism and naturalism [89, 92, 117, 120, 184-186].[18]

Operationalizing concepts and considering experiential data about stigma

The neuroscience of ethics is an area of inquiry sometimes rooted in pragmatism. Many disciplines and areas of inquiry prescribe a particular methodology and set of methods that align with a foundational epistemology and ontology. For example, inquiries in the natural sciences typically rely on *positivist* assumptions: a *realist* ontology suggesting that reality is 'out there' and an *objectivist* epistemology suggesting that the best way to know what is out there is through objective observation, data collection, and model-building. To understand this external and objective reality, we must ask the right questions, use the right methods, tools, and metrics, aiming to remove the observer and their influence from the observed phenomenon. In contrast, pragmatism often assumes a plurality of sources of knowledge and methods of interpretation, seeking to bridge the gaps between the natural sciences and humanities [184]. In this way, while social values, beliefs, and attitudes are understood to inform scientific knowledge production, it does not mean that such production is wrong or ineffective. Instead, we can understand the data produced through natural and social scientific inquiry – and other modes of inquiry – as both relevant and intimately connected to the context of the studied *situation* or phenomenon.

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[17] While beyond the scope of my thesis, see neuroethics scholarship on moral reasoning, which could contribute to a deeper understanding of FASD: the "agent-deed-consequence model of moral judgement" [182, 183].

[18] The neuroscience of ethics should be considered only one part of the evidentiary body that could inform a pragmatic and empirical approach to ethics. Other disciplines and related evidence must be considered in tandem with neuroscience evidence (e.g., psychology, sociology) to ensure a holistic response to a complex *situation*.

This makes pragmatism a highly contextualized approach to knowledge production and ethical deliberation, contrasting much of traditional philosophical ethics, which approaches questions of right and wrong in highly abstract, non-empirical, and universalist ways. Bioethics itself emerged as a means of finding more practically applicable approaches to the serious ethical challenges in real-world medical and research-based contexts. Pragmatic approaches to bioethics (drawing on the work of John Dewey) take it a step further, treating ethics theories and ethically relevant concepts as instrumentally useful – as tools – that can "foster human flourishing" [119]. In this way, pragmatic ethics and bioethics are "intrinsically empirical"; as in, we can empirically test our ethical concepts and principles through a variety of methodological approaches [155]. In my work, the concept of stigma – and the need to destigmatize FASD stakeholders – serves as such a tool, with the experiential data generated helping to animate further deliberation and explorations of the ethically fraught everyday *situations* FASD-related stakeholders may face.

Approaching *morally problematic situations* and the practice of research through a pragmatist lens [162] – and its related deliberative and fallibilist commitments [119] – enables us to combine insights, theories, and methods from multiple disciplinary approaches. Here, by instrumentalizing Link and Phelan's conception of stigma as a lens through which to understand challenges associated with FASD, alcohol, and pregnancy (Chapters 3 and 4), and as a concept to generate deliberation among relevant stakeholders (Chapter 5), we can better provide appropriate responses with the aim of supporting FASD stakeholders to flourish (Chapters 6 and 7).

Stigmatization and the development and employment of 'concepts-principles'

In a pragmatist approach to ethics, a concept like stigma is only instrumentally useful insofar as it helps us understand and describe the challenges associated with marginalization and helps free individuals from the constraints imposed on them. It is only in the context of a given person's lived experiences (and our goal to ameliorate the *situation*) that stigma holds meaning – i.e., that certain people are actively stigmatized in connection with their identity and excluded from many facets of everyday life with serious consequences for their well-being. Similarly, the concept of disablement as elaborated in the social model of disability is conceptually comparable to the notion of stigma, in that it concerns how certain groups of people (those with physical, physiological, or psychological differences) are marginalized. While stigma may apply to any identity category deemed salient in a given time, place, or context (e.g., race, gender, ability) – as does intersectionality – disablement is typically not.[19] In part, this helps explain why I employ both the concept of stigma and a social model of disability in my work – i.e., to help tease apart gendered and racialized experiences of birth mothers from the (perhaps similarly gendered and racialized but also) ability-related expectations of people with FASD themselves. Even then, this distinction may not be completely clear, as examples of challenges faced by birth mothers such as addiction could also be imagined through the lens of the social model of disability. Link and Phelan's model of stigma, therefore, serves an important but still instrumental purpose in my work. Itself a model informed by interdisciplinary theory and data from both social psychology and sociology, experimental and experiential data could inform shifts in the model's construction – e.g., perhaps other co-occurring elements exist, perhaps some elements need to be specified further, perhaps some elements need not co-occur to result in stigmatization, nonetheless.

While my work does not seek to challenge Link and Phelan's model of stigma, it does provide experiential evidence that supports their five co-occurring elements [50, 119] (Chapter 5

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[19] This is not always the case, as some debates exist about how a social model of disability could extend to any "spoiled" identity – which, in turn, raises difficult questions about what it would mean to conceive of race- or gender-based disadvantages as "disabling" rather than more broadly as discriminatory. This is beyond the scope of my thesis, though it is an interesting example that could help illustrate the power of interdisciplinary work tying together feminist frameworks like intersectionality, the concept of stigma broadly, and a social model of disability.

and 6; Appendix 2). In asking participants about their experience receiving the diagnostic label (labelling difference – see Appendix 2) and experiences of stereotypes and stereotyping (Chapter 5), we were able to identify participant experiences of the other elements of Link and Phelan's model: othering, discrimination, and power aligned against people with FASD and their families.

Diagnostic labelling appeared to contribute to participant stigmatization. However, many also reported positive or empowering experiences associated with labelling (See Appendix 2, Tables 2-3) – e.g., relief at finally having an explanation, the ability to connect with others in similar situations to both build a community and stand in solidarity. The mix of reactions (not just positive and negative, but even neutral) points to the various ways that FASD stakeholders may experience asymmetric effects associated with the elements of a process of stigmatization. In receiving a diagnostic label, they were also able to receive some element of understanding and support from some, while facing judgement and discrimination from others in everyday contexts.

Understanding complex moral situations in stakeholders' everyday lives

In bioethics scholarship, there seems to be a tendency to reason about what some call "dramatic ethics" challenges over "everyday ethics" challenges – everyday, as in, "issues that occur regularly… but that are perhaps under-discussed in light of their regularity or overlooked because they are perceived as ordinary and unimportant from an ethical standpoint" [118]. For, example, consider the amount of bioethics discourse that has focused on physician-assisted death compared to the minimal ethical discussions about suicide [187-189].[20] Physician-assisted dying reflects a situation that may not impact many Canadians, but which has serious consequences at the boundaries of acceptable medical and moral decision-making. However, ethical and public

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[20] This is not at all to suggest that dying by suicide is everyday, common, ordinary, or not serious in the way a term like 'dramatic' would suggest. However, it has been largely overtaken in discourse by the more striking and seemingly ethically fraught example of physician-assisted death – despite its serious and devastating impact.

discussion about dying by suicide outside of this context has been limited in comparison, despite being a leading cause of death globally [188]. For example, in a research encounter, were a participant to disclose suicidal ideation, the immediate ethical concern is likely not the question of whether dying by suicide is ethically permissible [189]. Instead, researchers need guidance and to reflect on their professional ethical obligations toward their participants. This example helps to frame the stakes of "dramatic" versus "everyday" ethics – where certain kinds of complex moral challenges are perceived as more worthy of attention. However, as our qualitative data suggest (and in the case of suicide), the complex world of everyday experiences can reveal everyday dilemmas as profound and messy as what might be considered "dramatic".

In my work, this emerged most clearly in Chapter 5 when exploring the impact of stereotypes about women who drink while pregnant on the lives of adoptive, foster, and kinship caregivers. We had conceived of the stigma associated with FASD as reverberating outwards from the diagnosis itself – impacting the individual first, and then the birth mother – but had not entirely anticipated the degree to which the stigma would also attach itself to other caregivers and even to professionals. For caregivers, what emerged was a serious moral dilemma regarding whether to disclose their status as a child's adoptive, foster, or kinship caregiver – as in, not the birth mother who consumed alcohol while pregnant. Caregivers, usually mothers, expressed a range of conflicted feelings about what they ought to do; in this case, they reflected on the ethical implications and tension associated with a double disclosure, first of their child's FASD and then of their parental status. When they chose to inform others about a child's diagnosis, caregivers described a (sometimes unasked) question that would linger until addressed: the issue of whether *they* had caused their child's impairments. Here, caregivers had to weigh several competing concerns: 1) disclosure to avoid judgemental attitudes; 2) disclosure to encourage positive treatment of them and their child;[21] 3) no disclosure, as they did not want to reinforce the idea that 'adoptive' is a necessary qualifier for their parenthood; and 4) no disclosure, to ensure that they did not shift the stigma onto more marginalized women. In understanding the contours of this common and yet fraught everyday experience (i.e., the contours of the *situation* in which such caregivers find themselves) we are better positioned to both offer prescriptive advice and to consider systemic changes to FASD discourse to avoid such collateral damage. My thesis does not seek to offer such advice directly but serves as a helpful elucidation of the context of caregivers that enables both reflection on this ethical dilemma and consideration of future research directions; ultimately, each caregiver's context may suggest a plurality of responses. We only know this difficult decision needs to be made at all because of the window that qualitative research can provide into the lives and *situations* of participants' everyday ethical challenges.

Future directions: Stigma associated with discourse on FASD, alcohol, and pregnancy

My thesis has sought to understand the public discourse about and the lived experiences of key FASD stakeholders: people with FASD, birth mothers, women who consume(d) alcohol while pregnant, caregivers (i.e., kinship, adoptive, foster), and healthcare and allied professionals (e.g., social workers in child welfare, addiction care counsellors, psychologists specializing in FASD assessment). In this work, we have teased apart some of the experiences of distinct stakeholder groups that are often lumped together (e.g., parents and children) with the aim of pointing to the complex ethical dilemmas and support needs of each group, focused on ways to shift and improve discourse that currently may contribute to and perpetuate the stigma they face.

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[21] In this case, I refer to the example of the adoptive parents who were treated poorly by hospital staff prior to disclosing the adoption (see Chapter 5). This example raised the possibility of poor provision of medical care (not specifically regarding the child's direct care, but in failing to treat the parents with respect in health decision-making processes). This concern extends beyond healthcare – caregivers considered whether to inform teachers, family, neighbours, and more, to varying degrees of negative and positive reception (see Appendix 2).

This discourse can be public (i.e., news, health campaigns) or interpersonal (i.e., with friends and family, with doctors and teachers, among members of the FASD community).

In Chapters 3 and 4, we studied the question of the information presented in Canadian print media; however, other kinds of media also need to be studied – television news, fictional accounts of FASD, alcohol, and pregnancy, digital news, social media, public health campaigns, court cases, and more. Additionally, our work did not directly reveal information about public understanding – more work must be done to learn about the public's views and to test the effects of different messaging on their understanding and beliefs. Others have begun to explore some of these questions (e.g., [124, 126, 130]), but our research suggests that more must be done.

In Chapters 5 and 6, we studied participants' lived experiences of FASD tied to public discourse, stigma, and stereotypes. In this way, we learned about the felt and perceived impact of possible stereotypes, as well as participant recommendations for how to communicate effectively and ethically. We learned about conflicting goals of different messaging (i.e., support versus prevention), possible target audiences (e.g., mothers, at-risk women, communities, people with FASD), and collateral stigma (or stigma by association). However, we did not learn directly about the lives of birth mother or women who drink while pregnant – we found it difficult to identify enough participants to recruit for focus groups and ultimately were unable to move ahead with that core category of FASD stakeholder. Other work has been done exploring the experiences of these stakeholders directly [69], but more can be done to bring those experiences into conversation with ethical considerations and challenges associated with stigmatization [125, 127]. For example, data on the interaction of fear-based campaigns and self-efficacy responses could be collected from women in general and particular groups of at-risk women [190]. Another identified gap could include teasing apart the social influences and biases informing FASD diagnostic processes. While it is commonly claimed that Indigenous people are more likely to receive a diagnosis of FASD – for good reason, given the evidence that does exist [123, 167]– there do not appear to be specific studies that explore the topic of racial bias and FASD. Finally, in adopting a pragmatist approach, more scholars could test and adjust different models of stigma (like Link and Phelan's), and could specify relevant concepts (e.g., self-stigma, self-efficacy).

Moving forward, my work suggests that we need to understand the impact of FASD-related stigma in messaging, education, and public discourse on each stakeholder group, and to explore the efficacy and ethics of alternate modes of messaging or intervention. Stigma can be far-reaching, impacting the treatment of key FASD stakeholders and informing the attitudes of professionals – pointing to the need for education materials targeting healthcare and allied professionals, teachers, and perhaps even journalists and science communicators. More work needs to be done to tease apart the positive and negative effects of prevention campaigns, public health messaging, and the active inclusion of people with FASD in messaging. One final area implied but not explored in my work could be to move beyond making existing messaging less stigmatizing: to design and study campaigns that aim to actively destigmatize all relevant FASD stakeholders – to ensure that they receive the best support possible and can grow and flourish.

Conclusion

A diagnosis of FASD, a heterogenous and controversial neurodevelopmental diagnosis resulting from alcohol exposure in the womb [4, 5, 14], invokes a complex web of relationships that can be difficult to tease apart. At the centre lies the individual with the diagnosis – a person impacted by prenatal alcohol exposure. Given its cause, and unlike most other diagnoses, the term FASD also communicates information about the birth mother. This may promote stigma against those birth mothers, as well as women who consume(d) alcohol while pregnant broadly

[49, 88, 191], despite myriad reasons why a person might drink (e.g., an abusive relationship, challenges with substance use, not knowing about an unplanned pregnancy [192]). Additionally, many children diagnosed with FASD have been identified in child welfare [167] after being removed from difficult family circumstances. Consequently, stigma faced by birth mothers can extend to adoptive, foster, or kinship caregivers, who may be assumed by others to be the parent that exposed a child to alcohol in the womb [180]. Indigenous peoples have also long been over-represented in child welfare and criminal justice systems (systems that appear to have higher prevalence of FASD [167]), having been uncritically connected to addiction stereotypes without reference to a history of systemic racism, colonialism, and residential schools in Canada [46]. Consequently, FASD has long been constructed as a problem only for marginalized groups in Canada and elsewhere [15], despite a growing body of evidence suggesting otherwise [123].

In this thesis, I explored how Canadian print media represents these overlapping and intersecting actors and explored the rich and troubling portrait of the *situation* in Canada – a portrait that raises ethical questions about reactions to and varied understandings of FASD stakeholders tied to race, class, and gender. In asking the question "what information is communicated by Canadian print media about FASD, alcohol, and pregnancy" we identified ethical and social challenges of science and health communication about FASD, alcohol, and pregnancy, and concerns about the portrayal of marginalized stakeholders. In asking the question "how do the stakeholders discussed by said news coverage react when shown that coverage" we were able to learn about the experiences of people with FASD, their caregivers, and FASD professionals. We learned about their experience of stereotyping and stigma, as well as their recommendations to shift and improve discourse on FASD, alcohol, and pregnancy. In bringing their everyday experiences into conversation with different bodies of literature (e.g., public health ethics, pragmatic bioethics, disability studies), we provided insight into the ethical challenges and moral dilemma that must be addressed and the work that remains to be done to understand the impact and efficacy of FASD messaging, prevention, and interventions. Scholars, clinicians, and communicators should attend to the lived experiences of people with FASD and their families, explore public and professional (e.g., doctor, journalist, social worker) educational tools, and carefully consider the use and impact of different messaging – from fear to hope. The goal is to promote not just success for FASD stakeholders, but their growth and flourishing.

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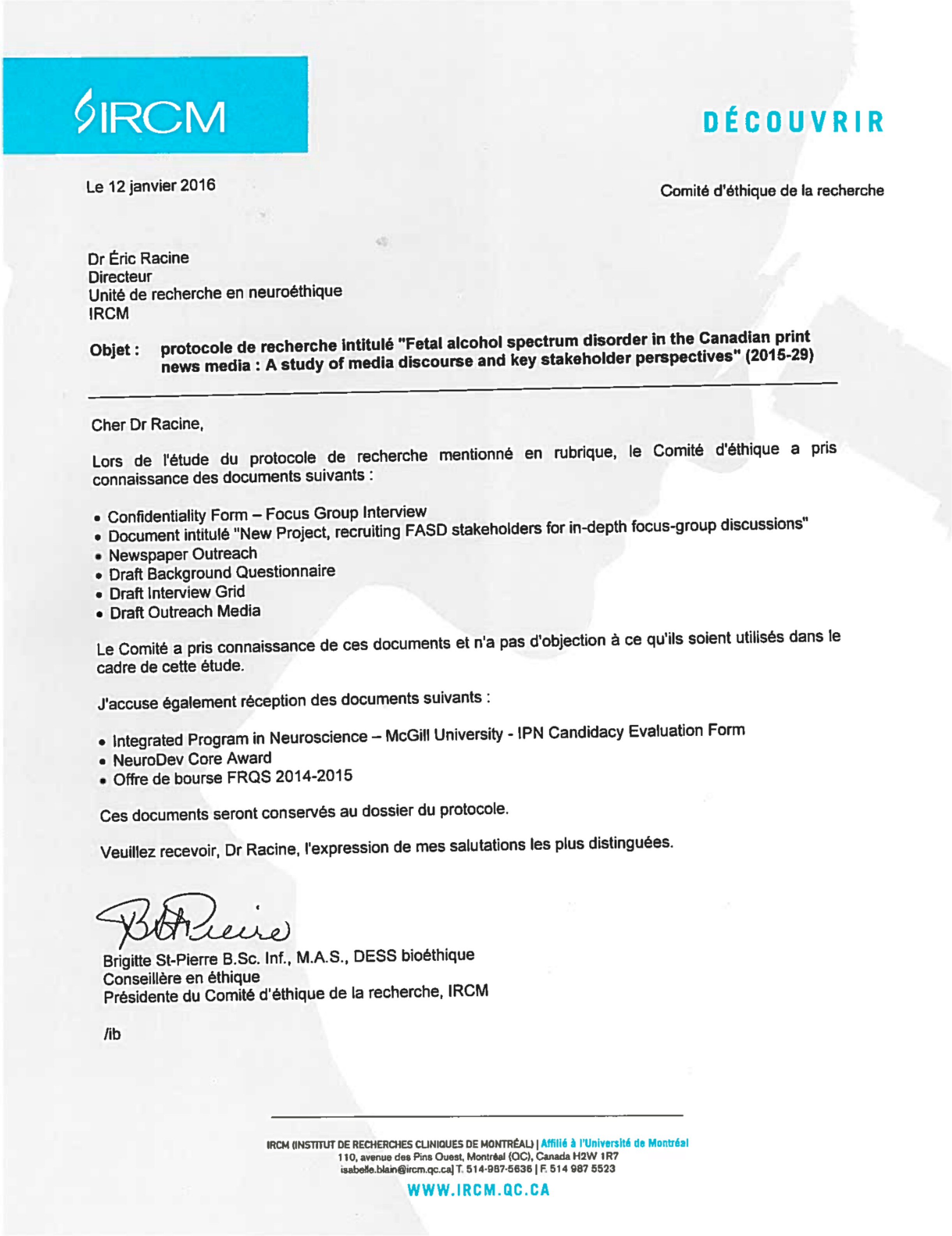
APPENDICES

Appendix 1: Interview Materials

Research Ethics Board Approval



IRCM

DÉCOUVRIR

Le 12 janvier 2016

Comité d'éthique de la recherche

Dr Éric Racine
Directeur
Unité de recherche en neuroéthique
IRCM

Objet : **protocole de recherche intitulé "Fetal alcohol spectrum disorder in the Canadian print news media : A study of media discourse and key stakeholder perspectives" (2015-29)**

Cher Dr Racine,

Lors de l'étude du protocole de recherche mentionné en rubrique, le Comité d'éthique a pris connaissance des documents suivants :

- Confidentiality Form – Focus Group Interview
- Document intitulé "New Project, recruiting FASD stakeholders for in-depth focus-group discussions"
- Newspaper Outreach
- Draft Background Questionnaire
- Draft Interview Grid
- Draft Outreach Media

Le Comité a pris connaissance de ces documents et n'a pas d'objection à ce qu'ils soient utilisés dans le cadre de cette étude.

J'accuse également réception des documents suivants :

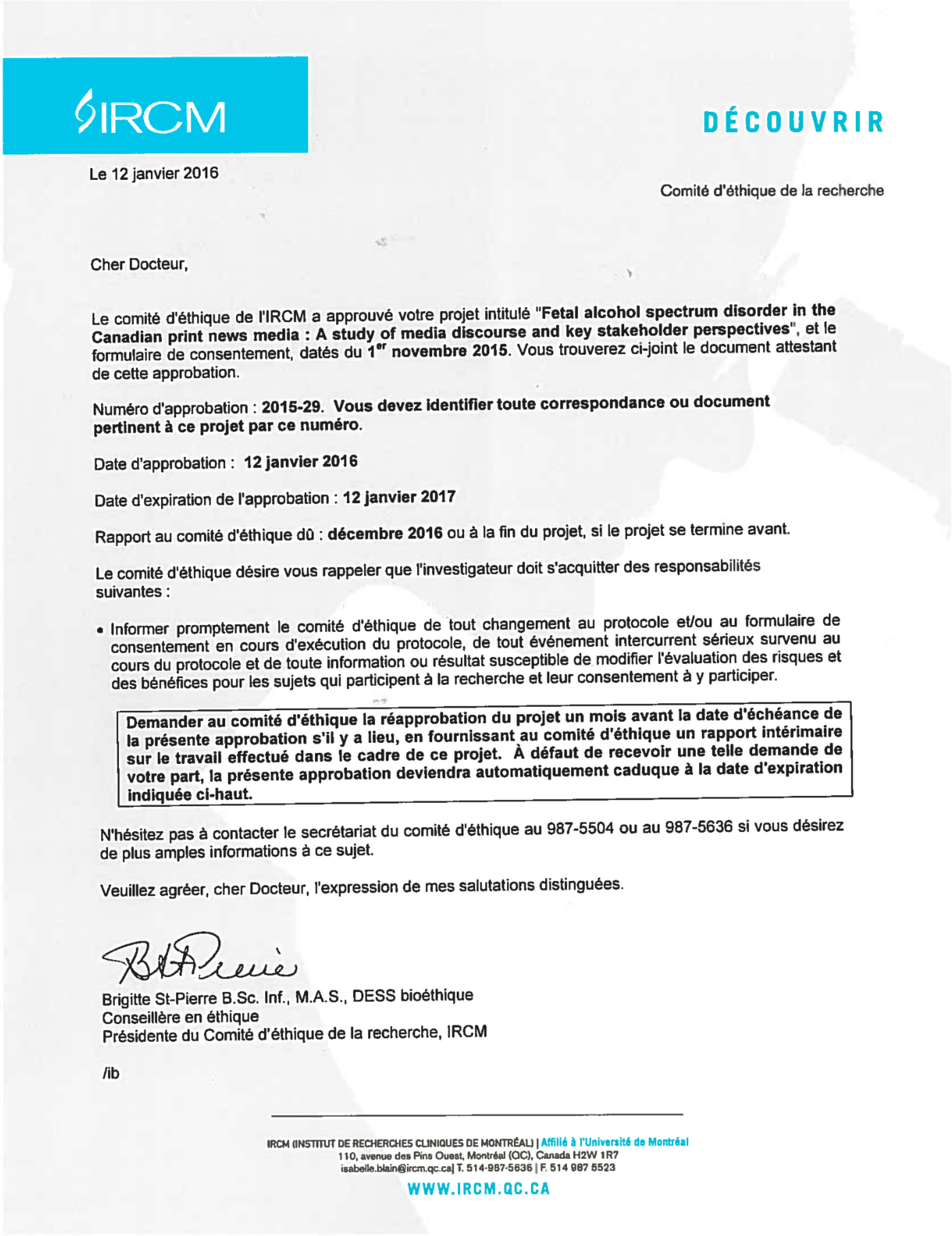
- Integrated Program in Neuroscience – McGill University - IPN Candidacy Evaluation Form
- NeuroDev Core Award
- Offre de bourse FRQS 2014-2015

Ces documents seront conservés au dossier du protocole.

Veuillez recevoir, Dr Racine, l'expression de mes salutations les plus distinguées.

Brigitte St-Pierre B.Sc. Inf., M.A.S., DESS bioéthique
Conseillère en éthique
Présidente du Comité d'éthique de la recherche, IRCM

/ib



IRCM

DÉCOUVRIR

Comité d'éthique de la recherche

Le 12 janvier 2016

Cher Docteur,

Le comité d'éthique de l'IRCM a approuvé votre projet intitulé "**Fetal alcohol spectrum disorder in the Canadian print news media : A study of media discourse and key stakeholder perspectives**", et le formulaire de consentement, datés du **1er novembre 2015**. Vous trouverez ci-joint le document attestant de cette approbation.

Numéro d'approbation : **2015-29. Vous devez identifier toute correspondance ou document pertinent à ce projet par ce numéro.**

Date d'approbation : **12 janvier 2016**

Date d'expiration de l'approbation : **12 janvier 2017**

Rapport au comité d'éthique dû : **décembre 2016** ou à la fin du projet, si le projet se termine avant.

Le comité d'éthique désire vous rappeler que l'investigateur doit s'acquitter des responsabilités suivantes :

- Informer promptement le comité d'éthique de tout changement au protocole et/ou au formulaire de consentement en cours d'exécution du protocole, de tout événement intercurrent sérieux survenu au cours du protocole et de toute information ou résultat susceptible de modifier l'évaluation des risques et des bénéfices pour les sujets qui participent à la recherche et leur consentement à y participer.

Demander au comité d'éthique la réapprobation du projet un mois avant la date d'échéance de la présente approbation s'il y a lieu, en fournissant au comité d'éthique un rapport intérimaire sur le travail effectué dans le cadre de ce projet. À défaut de recevoir une telle demande de votre part, la présente approbation deviendra automatiquement caduque à la date d'expiration indiquée ci-haut.

N'hésitez pas à contacter le secrétariat du comité d'éthique au 987-5504 ou au 987-5636 si vous désirez de plus amples informations à ce sujet.

Veuillez agréer, cher Docteur, l'expression de mes salutations distinguées.

Brigitte St-Pierre B.Sc. Inf., M.A.S., DESS bioéthique
Conseillère en éthique
Présidente du Comité d'éthique de la recherche, IRCM

/ib

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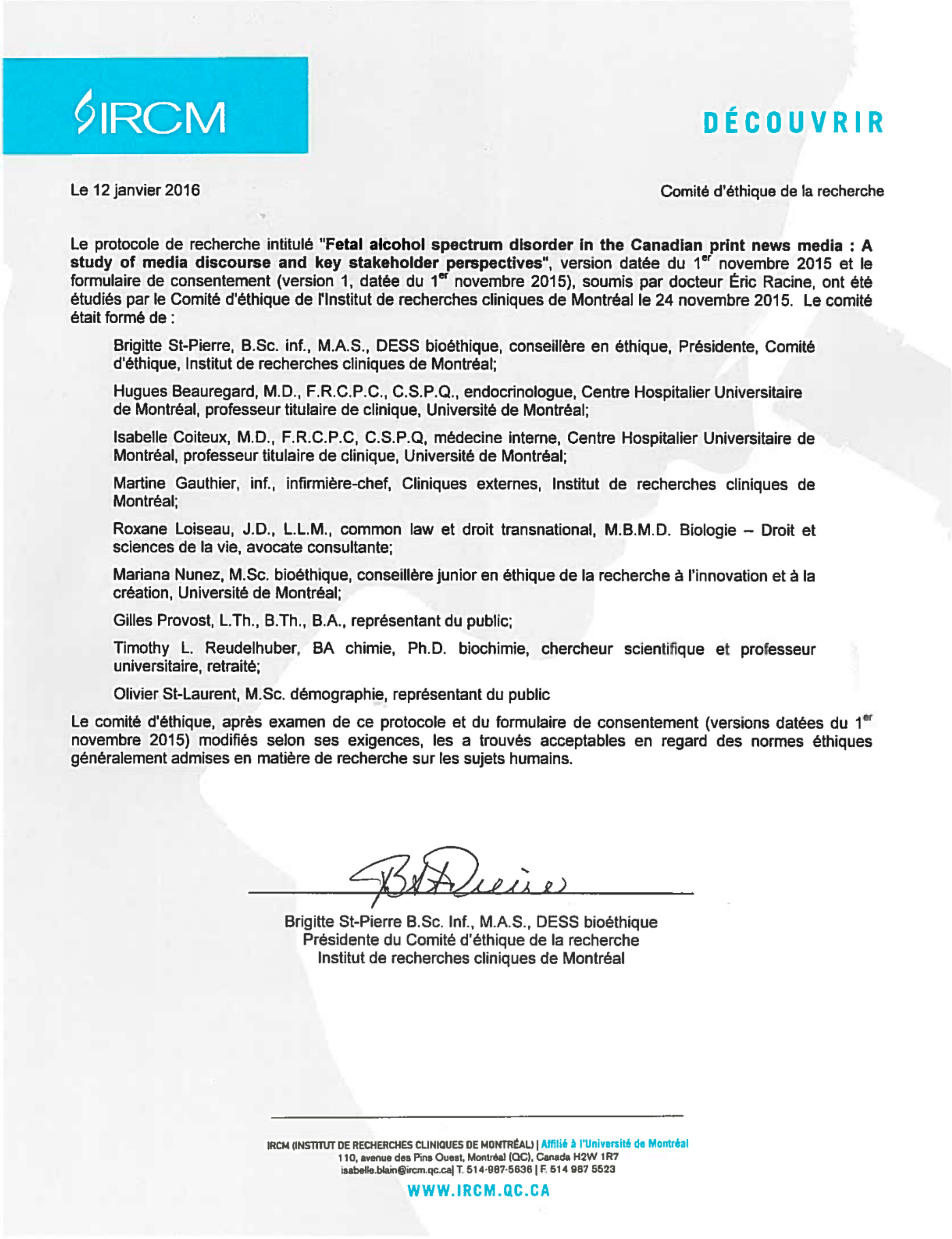

IRCM

DÉCOUVRIR

Le 12 janvier 2016

Comité d'éthique de la recherche

Le protocole de recherche intitulé "**Fetal alcohol spectrum disorder in the Canadian print news media : A study of media discourse and key stakeholder perspectives**", version datée du 1er novembre 2015 et le formulaire de consentement (version 1, datée du 1er novembre 2015), soumis par docteur Éric Racine, ont été étudiés par le Comité d'éthique de l'Institut de recherches cliniques de Montréal le 24 novembre 2015. Le comité était formé de :

> Brigitte St-Pierre, B.Sc. inf., M.A.S., DESS bioéthique, conseillère en éthique, Présidente, Comité d'éthique, Institut de recherches cliniques de Montréal;
>
> Hugues Beauregard, M.D., F.R.C.P.C., C.S.P.Q., endocrinologue, Centre Hospitalier Universitaire de Montréal, professeur titulaire de clinique, Université de Montréal;
>
> Isabelle Coiteux, M.D., F.R.C.P.C, C.S.P.Q, médecine interne, Centre Hospitalier Universitaire de Montréal, professeur titulaire de clinique, Université de Montréal;
>
> Martine Gauthier, inf., infirmière-chef, Cliniques externes, Institut de recherches cliniques de Montréal;
>
> Roxane Loiseau, J.D., L.L.M., common law et droit transnational, M.B.M.D. Biologie – Droit et sciences de la vie, avocate consultante;
>
> Mariana Nunez, M.Sc. bioéthique, conseillère junior en éthique de la recherche à l'innovation et à la création, Université de Montréal;
>
> Gilles Provost, L.Th., B.Th., B.A., représentant du public;
>
> Timothy L. Reudelhuber, BA chimie, Ph.D. biochimie, chercheur scientifique et professeur universitaire, retraité;
>
> Olivier St-Laurent, M.Sc. démographie, représentant du public

Le comité d'éthique, après examen de ce protocole et du formulaire de consentement (versions datées du 1er novembre 2015) modifiés selon ses exigences, les a trouvés acceptables en regard des normes éthiques généralement admises en matière de recherche sur les sujets humains.

Brigitte St-Pierre B.Sc. Inf., M.A.S., DESS bioéthique
Présidente du Comité d'éthique de la recherche
Institut de recherches cliniques de Montréal

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Outreach Flyer

Participants wanted for a group interview study about FASD!

We want to talk to you about your experiences with FASD. In particular, we want to hear your thoughts and feelings about examples of Canadian FASD media coverage, to think about how to communicate information more effectively in the future. Your perspective will be invaluable in helping us understand FASD, public perception, and public messaging.

Who can participate?
We will include key stakeholders, like: 1) adults with FASD; 2) parents and caregivers of people with FASD; 3) healthcare professionals with experience diagnosing or caring for patients with FASD & their families; and 4) FASD communicators (e.g., journalists, public health officials).

What does the study look like?
This study will involve participation in a 2-hour focus group interview in English, where we will discuss issues surrounding diagnosis, stereotyping, and media coverage. Each group interview will only include one stakeholder group at a time (e.g., only adults with FASD, only parents).

You will be compensated for your time.

How can I get involved?
If you feel you match the above criteria, please send an email to: **john.aspler@ircm.qc.ca**.

We will send you a brief online questionnaire to fill out, as well as the informed consent document for you to look over when deciding whether or not to participate. Sending us an email does not mean you have agreed to participate, and you can choose to stop at any time.

For more information or if you have any questions, please contact John Aspler at: **john.aspler@ircm.qc.ca**, or at (514) 987-5500 (extension 3356).

Study Title: Fetal alcohol spectrum disorder in the Canadian print media: A study of media discourse and key stakeholder perspectives

This study is conducted by an interdisciplinary team of bioethicists and scientists:

John Aspler, BSc, Doctoral candidate, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM).

Eric Racine, PhD, Director of the Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM), 110 avenue des Pins Ouest, Montréal QC H2W 1R7, Tel.: 514 987-5723, email: eric.racine@ircm.qc.ca.

James Reynolds, PhD, Centre for Neuroscience Studies, Queens University.

Screening and Recruitment Questionnaire

FASD Interview Study (Digital Form)

Thank you so much for your interest in our focus group interview study about FASD and the media.

This survey is a 5-minute questionnaire that will help us collect some basic details to help us choose participants, and to help us learn about the types of people who are answering our questions.

Please note that although we will ask you for your email address in this survey, your information will remain private. Your answers will only be seen by the research team.

Filling out this survey does not mean that you consent to take part in the interviews. We will follow up with you by e-mail when you finish the survey.

If you have any questions, before or after filling out this questionnaire, please feel free to contact me at: john.aspler@ircm.qc.ca

Please choose or write an answer for the questions below:

* 1. Have you ever heard of FASD? Yes/No
* 2. To your knowledge, what causes FASD? ____________________
* 3. Please list some symptoms of FASD ____________________

FASD Interview Study - Background Information

Please respond to the following prompts:

* 4. Your age (in years) ____________________
* 5. Your gender ____________________
* 6. Your race or ethnicity ____________________
* 7. Your first language ____________________
* 8. What city do you currently live in? ____________________

* 9. What level of education have you completed (please select one)?

- Elementary school
- High school graduate
- CEGEP/technical college
- Undergraduate degree
- Professional degree
- Graduate degree

* 10. What is your employment status (please select all that apply)?

- Full time worker
- Part time worker
- Full-time student
- Part-time student
- Volunteer
- Not employed
- Retired

Adults with FASD

* 11. Are you an adult with FASD? Yes/No

If yes –

* 12. How old were you when you first realized, or were first told, that you had FASD?
13. Do you have anything you would like to add to that answer? _________________

Parents of a person with FASD – Biological

* 14. Are you the biological mother of a person with FASD? Yes/No

If yes –

* 15. How old was your child when you first realized, or were first told, they had FASD?
16. Do you have anything you would like to add to that answer? _________________

Parents of a person with FASD – Kinship Caregiver

* 17. Are you a family member caring for a person with FASD (e.g., uncle, grandma)? Yes/No

If yes –

* 18. How old was your child when you first realized, or were first told, they had FASD?
19. Do you have anything you would like to add to that answer? _________________

Parents of a person with FASD – Foster

* 20. Are you the foster parent of a person with FASD? Yes/No

If yes –

* 21. Did you know your child had FASD before you began to foster them? Yes/No
22. If no, how long after you began to foster them did you first realize, or were you first told, that they had FASD?
* 23. How old was your child when you first realized, or were first told, they had FASD?
24. Do you have anything you would like to add to that answer? _________________

Parents of a person with FASD – Adoptive

* 25. Are you the adoptive parent of a person with FASD?

If yes –

* 26. Did you know your child had FASD before you adopted them? Yes/No

27. If no, how long after you adopted them did you first realize, or were you first told, that they had FASD?
* 28. How old was your child when you first realized, or were first told, they had FASD?
29. Do you have anything you would like to add to that answer? _________________

Healthcare professionals
* 30. Are you a healthcare professional with experience caring for people with FASD?
Yes/No

If yes –
* 31. What is your healthcare profession? _________________
32. Do you have anything you would like to add to that answer? _________________

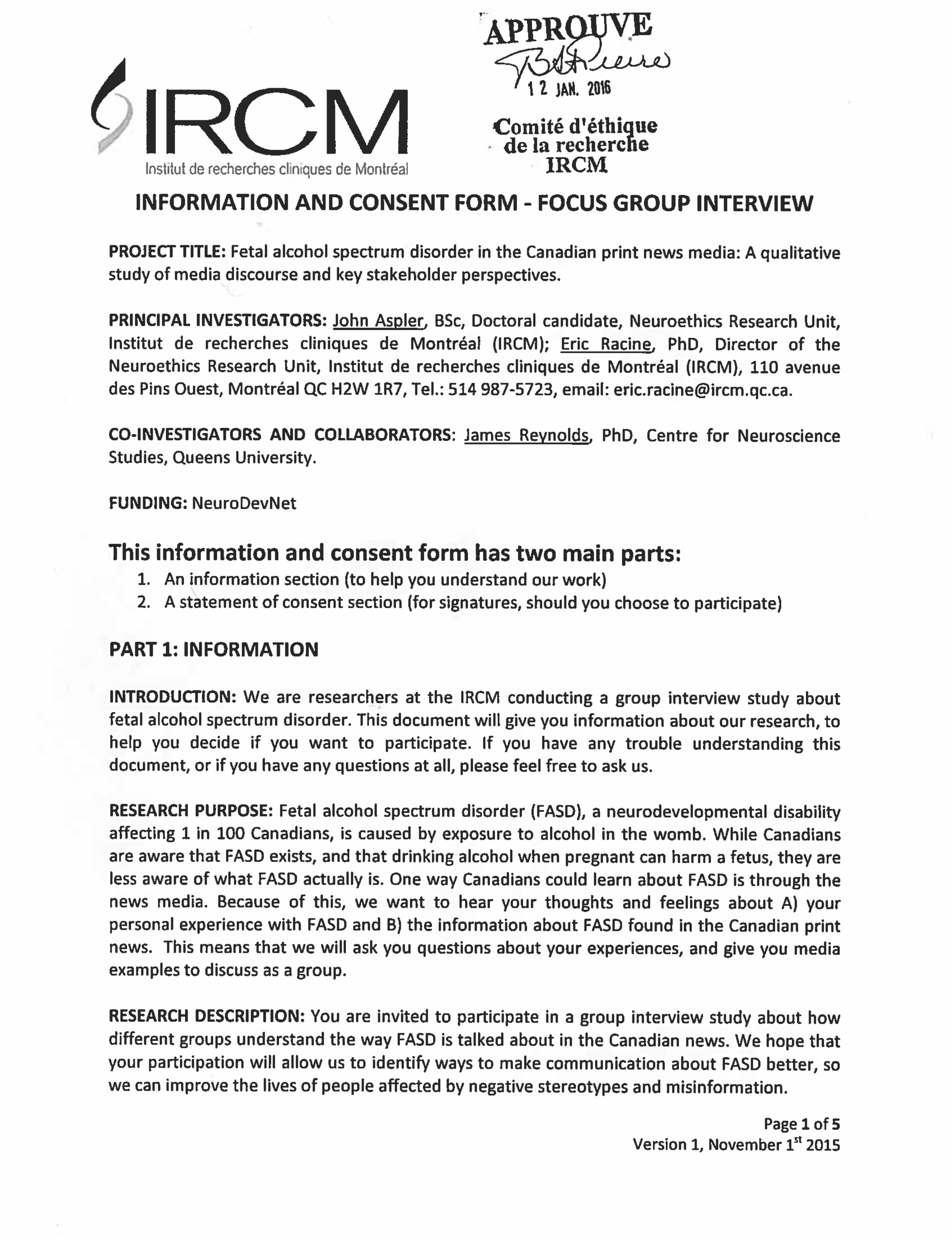
Health and science communicators
* 33. Are you a health or science communicator?

If yes –
* 34. What is your communication profession? _________________
35. Do you have anything you would like to add to that answer? _________________

FASD Interview Study – Contact information
* 36. Please include an email address, so that we can follow-up with you about taking part in our group interview study _________________

* 37. Would you like us to contact you to take part in future research besides this study?
Yes/No

Informed Consent Document



IRCM
Institut de recherches cliniques de Montréal

APPROUVE
12 JAN. 2016
Comité d'éthique
de la recherche
IRCM

INFORMATION AND CONSENT FORM - FOCUS GROUP INTERVIEW

PROJECT TITLE: Fetal alcohol spectrum disorder in the Canadian print news media: A qualitative study of media discourse and key stakeholder perspectives.

PRINCIPAL INVESTIGATORS: John Aspler, BSc, Doctoral candidate, Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM); Eric Racine, PhD, Director of the Neuroethics Research Unit, Institut de recherches cliniques de Montréal (IRCM), 110 avenue des Pins Ouest, Montréal QC H2W 1R7, Tel.: 514 987-5723, email: eric.racine@ircm.qc.ca.

CO-INVESTIGATORS AND COLLABORATORS: James Reynolds, PhD, Centre for Neuroscience Studies, Queens University.

FUNDING: NeuroDevNet

This information and consent form has two main parts:

1. An information section (to help you understand our work)
2. A statement of consent section (for signatures, should you choose to participate)

PART 1: INFORMATION

INTRODUCTION: We are researchers at the IRCM conducting a group interview study about fetal alcohol spectrum disorder. This document will give you information about our research, to help you decide if you want to participate. If you have any trouble understanding this document, or if you have any questions at all, please feel free to ask us.

RESEARCH PURPOSE: Fetal alcohol spectrum disorder (FASD), a neurodevelopmental disability affecting 1 in 100 Canadians, is caused by exposure to alcohol in the womb. While Canadians are aware that FASD exists, and that drinking alcohol when pregnant can harm a fetus, they are less aware of what FASD actually is. One way Canadians could learn about FASD is through the news media. Because of this, we want to hear your thoughts and feelings about A) your personal experience with FASD and B) the information about FASD found in the Canadian print news. This means that we will ask you questions about your experiences, and give you media examples to discuss as a group.

RESEARCH DESCRIPTION: You are invited to participate in a group interview study about how different groups understand the way FASD is talked about in the Canadian news. We hope that your participation will allow us to identify ways to make communication about FASD better, so we can improve the lives of people affected by negative stereotypes and misinformation.

PARTICIPANT SELECTION: As a member of one of four key groups, we feel that you have a great deal of relevant knowledge and experience that could contribute a lot to our understanding of media messages about FASD. These groups include: 1) people with FASD; 2) parents of people with FASD; 3) healthcare professionals; and 4) journalists and health communicators.

STUDY PROCEDURES: This study consists of a 2-hour semi-structured focus group interview, which will be audio-taped. Two non-participants will be present while you discuss questions asked by a moderator in a small group of 5-8: 1) the moderator; and 2) a note-taker and social worker who will provide you with support as needed. If you choose to participate, the interview will explore your experience with and understanding of FASD as a diagnosis and as a social label. Your group will only be made up of people from one of the four groups listed above. For example, if you have an FASD, so will everyone else taking part in your group discussion.

Please note that you may be asked to take part in a one-on-one interview, rather than a group discussion. This will only happen if we run into practical problems, like if we have trouble recruiting enough people for a group interview.

VOLUNTARY PARTICIPATION AND RIGHT TO WITHDRAW: You should not feel obligated to agree to participate in this project. If you have read this form and you do decide to participate, please understand that your participation is entirely voluntary. You have the right to refuse to answer particular questions. If you first agree to participate and then change your mind, you are free to withdraw your consent and discontinue your participation at any time, including during the interview. Please inform the principal investigator if you wish to withdraw from the study. If you choose to withdraw, we will destroy all the results which concern you, except those which are already analyzed in order to preserve the integrity of the study. If you withdraw from the group interview while it is ongoing, we will destroy data pertaining to you after transcription, so as to preserve the data of other participants. You will be told of any important new information learned during the course of this research which might affect your willingness to continue participating in this study.

RISKS: There are no known risks associated with participation in this study other than 1) the unlikely event of a breach of confidentiality (see **Confidentiality** section below); and 2) the potential for the interview to generate discomfort about the topic discussed. We will ensure the presence of a psychologist or social worker who will be ready to help you should you experience any emotional distress. This support person can also help debrief you after the focus group discussion, or can confidentially be reached by email after the study has ended. Note that disrespectful behaviour toward other participants will not be tolerated. If you behave disrespectfully, you risk being asked to leave.

BENEFITS: There are no known benefits to you associated with participation in this study, but results of the study will be used to inform better communication about FASD.

CONFIDENTIALITY: By agreeing to participate in this study, you agree to not tell people outside of this group interview anything said in the context of the discussion. This is to ensure that you do not share the private information, experiences, and stories of other participants. As an added way to help protect privacy, we will ask you to sign a separate confidentiality form.

The interview will be audio-recorded and transcribed *verbatim* by professional transcribers. Your identity and the information you provide will remain entirely confidential through an alphanumeric coding system that we have developed and that will be available only to the investigators. Information about the coding system will be kept in a secure location and access limited to study personnel. Your privacy will be maintained in all published and written data resulting from the study. Only the investigators and their research personnel will have access to the study data. The original data will be kept in a locked filing cabinet and documents will be coded before analysis. Data analysis will be performed on a password-protected computer.

The data collected will only be used to respond to the objectives of this study, as described in this consent form. All research data, including audio recordings, transcripts, and analyses, will be destroyed 7 years after completion of the study. Dr. Eric Racine will be responsible for supervising the destruction of data, including digital deletion of your audio recordings and shredding of transcripts and notes

The results of this study could be published in specialized publications or be the subject of academic discussions, but we will not identify you. Moreover, if results stemming from your participation are reported, they will be reported in a way that others will not be able to identify you (i.e., using an alphanumeric code and not your name).

For quality assurance your research file may be reviewed by the quality assurance officer of the institutions, ethics committees, or funding agencies involved. All third parties from these organizations will be bound by strict confidentiality policies.

You have the right to review your research folder to verify the data collected and to correct them as needed for as long as the primary investigator of the project, or the institution of the study, possess this information. However, in order to preserve the scientific integrity of the project, you may only have access to certain information once your participation has ended.

COMPENSATION: In recognition of your participation we will compensate you with a cheque of $100 for travel and transportation costs, as well as lost time, mailed to you after completion of the study.

LEGAL RIGHTS: By accepting to participate in this project, you are neither waiving any of your legal rights nor discharging the researchers or the institutions involved of their civil and professional responsibilities.

CONTACT INFORMATION: If you have any questions about this study, you may contact the primary investigator, John Aspler, at (514) 987-5500 (Ext: 3356). If you have questions about your rights as a research participant in this research project, or for any other complaint or comments, you may contact the Local Complaints and Quality Service Commissioner at the Hôtel-Dieu Hospital (CHUM) at 514-890-8000, extension 12761.

RESOURCES: If you have any other concerns at all, or need support, please follow this link to a list of excellent resources for FASD across Canada:
http://neurodevnet.ca/resources/fasd-resources/package

PART 2: STATEMENT OF CONSENT

*YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PERSON OBTAINING CONSENT, THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED, AND THAT A COPY OF THIS FORM HAS BEEN GIVEN TO YOU.

____
Name of Subject (Printed)

________________________________ ________________
Signature of Subject Date

Optional: I give the researchers permission to contact me about participation in future research on this topic, and to provide feedback about the results of this work:

____
Signature of Subject

FOR THE PERSON OBTAINING CONSENT:

I attest that the requirements for informed consent for the research project described in this form have been satisfied, that I have discussed the research project with the subject and explained to him or her in non-technical terms all of the information contained in this informed consent form, including any risks and benefits that may reasonably be expected to occur. I further certify that I encouraged the subject to ask questions and that all questions asked were answered.

________________________________ ________________
Signature of Person Obtaining Consent Date

The researcher agrees to comply with the study design and to ensure the safety of participants and to respect confidentiality.

Participant Confidentiality Agreement

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CONFIDENTIALITY FORM - FOCUS GROUP INTERVIEW

Before we begin the study, please read and sign the following confidentiality agreement. Given the sensitive and personal nature of the ideas that will be discussed in this group interview, we want to ensure that you do not share information given by other participants with people outside of the study.

By signing below, I agree to keep all information about the interview, including all concepts or ideas discussed, and personal stories shared, completely confidential. I agree to not disclose this information to anyone else outside of the study.

*YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, AND THAT YOU AGREE TO KEEP THE INFORMATION SHARED BY THE OTHER PARTICIPANTS CONFIDENTIAL

____
Name of Subject (Printed)

___________________________________ _________________
Signature of Subject Date

Interview Grid

Thank you so much for being here today. My name is John, and I am a PhD student at IRCM and McGill University. In my work, I study the experiences of people affected by disability. Today, I am going to ask you questions about your experiences with FASD, alcohol, and pregnancy.

Our main goal is to listen to what you have to say – and to get feedback about the way FASD is portrayed in Canadian news. Everyone participating today is/has [specific stakeholder group].

This discussion will last two hours and will be audio-recorded. No one else but the researchers and transcriber will have access to these recordings, and your identities will be kept confidential. To compensate you for your time, you will receive a 100$ cheque by mail in a few weeks.

Ground rules:

1. Please be respectful of others. Remember, there are no right or wrong answers!
2. It is important to respect each other's privacy. When we're done, please don't share other people's personal stories outside this room. That's why you signed a confidentiality form.
3. Feel free to share your thoughts, but make sure to give everyone a chance to speak.

Does anyone have any questions?

Awesome, so why don't we start by introducing ourselves? It would be great if each of you could take a minute to briefly tell everyone a little bit about who you are, and what your journey or experience with FASD has been. And don't worry – we'll have plenty of time later in the interview to discuss more of your ideas and experiences.

1. **Diagnosis**
    a. People with FASD:
        i. What was it like to first realise you might have FASD?
        ii. What is it like to tell others you have FASD – how have they reacted?
    b. Healthcare professionals:
        i. What is it like to tell a patient or their family that they might have FASD?
            1. If that is not your area of expertise, how does learning they might have FASD affect your patients/clients and their families? What kinds of reactions have you seen or heard about?
        ii. How have others reacted to your patients/clients after finding out? How have you reacted to them?
    c. Biological mothers:
        i. What was it like to first realise your child(ren) might have FASD?
        ii. What is it like to tell other people your child(ren) have FASD – how have they reacted?
    d. Adoptive parents:
        i. What was it like to first realize your child(ren) might have FASD?
        ii. What is it like to tell other people your child(ren) have FASD – how have they reacted?

This next question is about FASD and stereotypes. Stereotypes are common ways to describe groups of people (like men or women), even though there are huge differences between each person. For example: saying that all women like the colour pink ignores the fact that plenty of women do not like pink at all. Stereotypes can also seem positive, like saying that some groups are always very clean, or negative, like saying that some groups are always messy.

Does anyone have any questions?

2. **Stereotypes:**
    a. People with FASD:
        i. What kind of stereotypes do you think exist, if any, about FASD or people with FASD?
        ii. Do you think that there are any stereotypes about women who drink while pregnant? Like what?
        iii. Have these stereotypes ever affected you or a loved one, and if so, how?
    b. Healthcare professionals:
        i. What kind of stereotypes do you think exist, if any, about FASD or people with FASD?
        ii. What kind of stereotypes do you think exist, if any, about women who drink while pregnant?
        iii. Have these stereotypes ever affected your patients or their families and loved ones, and if so, how?
    c. Biological mothers:
        i. What kind of stereotypes do you think exist, if any, about FASD or people with FASD?
        ii. What kind of stereotypes do you think exist, if any, about women who drink while pregnant?
        iii. Have these stereotypes ever affected you or your child, and if so, how?
    d. Adoptive parents:
        i. What kind of stereotypes do you think exist, if any, about FASD or people with FASD?
        ii. What kind of stereotypes do you think exist, if any, about women who drink while pregnant?
        iii. Have these stereotypes ever affected you or your child, and if so, how?

Now we're going to show you how people with FASD, and women who drink while pregnant, have been talked about in the Canadian news media. These quotes come from our previous work, where we analyzed roughly 300 news articles about FASD, published in newspapers between 2002 and 2015. We chose quotes that span a wide range of perspectives, and we're looking for your initial reactions to them, and anything you feel you would keep or change if you were the one talking about the topic. This could be specific words or sentences, or it could even be the general framing or context of the quote being presented.

Some examples might seem controversial, or shocking, but we wanted to show you some of the more extreme reports and quotes. We are also sharing with you content illustrative of these extremes, which do not always reflect the most frequent ways of talking about FASD.

Have you ever read or seen coverage of FASD in the media before?

3. **Media Questions for each slide:**
    a. How do you feel about what is being communicated here?
    b. Would you have said something differently?
    c. What else would you want to say on this topic?

4. **Closing the discussion**
    a. What kind of positive stories do you wish would be told about FASD?
    b. Keeping yourself / your child / your clients in mind, what strengths do you wish would be discussed?
    c. Is there anything else you want to talk about, or that you feel we haven't had a chance to discuss today?

Thank you all so much for being here today.

If you have any questions, please feel free to contact me.

Interview Coding Framework

Questions that should help guide the analysis

1. What is it like for them, experientially?
2. What stereotypes do they raise, what are the implications, are they discussed outside stereotype section?
3. How do people react to media coverage?
4. What should we do about media coverage or public narratives about FASD, alcohol, and pregnancy?

Personal Experiences → What is it like for them?

1. **Participant characteristics**
2. **Support for people with FASD and their families**
   a. Supportive
      i. Supportive individuals
         1. Person with FASD account of supportive individuals
         2. Caregiver account of supportive individuals
         3. HCAP account of supportive individuals
      ii. Supportive institutions
         1. Person with FASD account of supportive institutions
         2. Caregiver account of supportive institutions
         3. HCAP account of supportive institutions
   b. Unsupportive
      i. Unsupportive individuals
         1. Person with FASD account of unsupportive individuals
         2. Caregiver account of unsupportive individuals
         3. HCAP account of unsupportive individuals
      ii. Unsupportive institutions
         1. Person with FASD account of unsupportive institutions
         2. Caregiver account of unsupportive institutions
         3. HCAP account of unsupportive institutions
   c. Concerns about a lack of support or a need for more support
   d. Interventions
3. **Experience of a potential FASD diagnosis**
   a. The diagnostic process
      i. Experiences of people with FASD
         1. Self-reported
            a. Diagnostic journey
            b. Reactions to a potential diagnosis
            c. Stakeholder-directed diagnosis
         2. Caregiver-reported
            a. PWFASD diagnostic journey
            b. PWFASD reactions to a potential diagnosis
            c. PWFASD-directed diagnosis
         3. HCAP-reported
            a. PWFASD diagnostic journey
            b. PWFASD reactions to a potential diagnosis
            c. PWFASD-directed diagnosis
      ii. Experiences of birth mothers or families
         1. HCAP-reported
            a. BM and BF diagnostic journey
            b. BM and BF reactions to a potential diagnosis

        - iii. Experiences of caregivers
            - 1. Caregiver-reported
                - a. Diagnostic journey
                - b. Reactions to a potential diagnosis
                - c. Stakeholder-directed diagnosis
            - 2. HCAP-reported
                - a. CG diagnostic journey
                - b. CG reactions to a potential diagnosis
        - iv. Experiences of HCAPs
            - 1. Decisions about diagnosis
            - 2. Reactions to a potential diagnosis
    - b. Disclosing a potential diagnosis
        - i. Decisions about disclosure
            - 1. People with FASD decisions about disclosure
            - 2. Caregiver or birth mother decisions about disclosure
            - 3. HCAP decisions about disclosure
        - ii. Consequences of decisions to disclose or not
            - 1. Consequences of disclosure for people with FASD
            - 2. Consequences of disclosure for caregivers
    - c. Understanding FASD
        - i. Gateway to people with FASD understanding themselves
        - ii. Gateway to caregivers and birth mothers understanding their child(ren) or themselves
        - iii. Gateway to HCAPs understanding their patients/clients or their families
        - iv. Others: Understanding FASD and women who drink while pregnant
        - v. Advocacy & Training
    - d. Usefulness of the diagnosis
- **4. Positive experiences**
    - a. Strengths
        - i. Self-reported accounts of strengths
        - ii. Caregiver-reported accounts of their child’s strengths
        - iii. HCAP-reported accounts of a client or patient’s strengths
    - b. Accomplishments
        - i. “Our accomplishments”
        - ii. Caregiver-reported accounts of their child’s accomplishments
        - iii. HCAP-reported accounts of a client or patient’s accomplishments
    - c. Birth mother strengths and accomplishments
- **5. Challenging experiences**
    - a. Challenges faced by people with FASD
        - i. Self-reported accounts of FASD-related challenges
        - ii. Caregiver-reported accounts of their child’s challenges
        - iii. HCAP-reported accounts of a client or patient’s challenges
    - b. Challenges faced by caregivers (e.g., martial issues)
        - i. Person with FASD-reported accounts of caregiver challenges
        - ii. Self-reported accounts of caregiver challenges
        - iii. HCAP-reported accounts of challenges faced by caregivers
    - c. Professional challenges faced by HCAPs related to FASD
    - d. Challenges faced by birth mothers (e.g., abuse, poor service provision, others lack empathy)
        - i. Person with FASD-reported accounts of challenges faced by birth mothers
        - ii. Caregiver-reported accounts of challenges faced by birth mothers
        - iii. HCAP-reported accounts of challenges faced by birth mothers

6. **Relationships with other stakeholders**
    a. Person with FASD and birth mother or family
    b. Caregiver and birth mother or family
    c. Person with FASD and caregiver or caregiver's family
    d. HCAP with birth mother
    e. HCAP with person with FASD
7. **Other**
    a. Experiences and discussions about sigma
    b. Discussions about coping strategies
    c. Discussions about age-related factors tied to FASD
    d. Solidarity among participants with FASD

Stereotypes → What have they heard or experienced?

1. **FASD stereotypes**
    a. Explicit FASD stereotypes
    b. Implicit FASD stereotypes
    c. Impact of FASD stereotypes
2. **Birth mother stereotypes**
    a. Explicit birth mother stereotypes
    b. Implicit birth mother stereotypes
    c. Impact of birth mother stereotypes
3. **Caregiver stereotypes**
    a. Explicit caregiver stereotypes
    b. Implicit caregiver stereotypes
    c. Impact of caregiver stereotypes

Media Reactions → How do participants feel about this coverage?

1. **Participant reactions to media content**
    a. People with FASD
        i. Agreement with media content
            1. Preferences for certain terms/quotes/ideas
            2. Rationale for why they're good/right/just
        ii. Disagreement with media content
            1. Dislike of or disagreement with certain terms/quotes/ideas
            2. Rationale for why they're bad/wrong/unjust
        iii. Sources of confusion (e.g., words like scourge)
        iv. Dialogue between participants
    b. Caregivers for people with FASD
        i. Agreement with media content
            1. Preferences for certain terms/quotes/ideas
            2. Rationale for why they're good/right/just
        ii. Disagreement with media content
            1. Dislike of or disagreement with certain terms/quotes/ideas
            2. Rationale for why they're bad/wrong/unjust
        iii. Sources of confusion (e.g., words like scourge)
        iv. Dialogue between participants
    c. Healthcare and allied professionals
        i. Agreement with media content
            1. Preferences for certain terms/quotes/ideas
            2. Rationale for why they're good/right/just

        ii. Disagreement with media content
            1. Dislike of or disagreement with certain terms/quotes/ideas
            2. Rationale for why they're bad/wrong/unjust
        iii. Sources of confusion (e.g., words like scourge)
        iv. Dialogue between participants

2. **Participant modifications, suggestions, and recommendations: What should we do about coverage?**
    a. People with FASD
        i. Suggestions for how to modify media content
            1. Changing words, phrases, or entire quotes
            2. Further context required
        ii. Recommendations for communicating about FASD
    b. Parents of people with FASD
        i. Suggestions for how to modify media content
            1. Changing words, phrases, or entire quotes
            2. Further context required
        ii. Recommendations for communicating about FASD
    c. Healthcare and allied professionals
        i. Suggestions for how to modify media content
            1. Changing words, phrases, or entire quotes
            2. Further context required
        ii. Recommendations for communicating about FASD
3. **Discussions about FASD-related media discourse beyond reactions**
    a. Prior experience with FASD-related media coverage
    b. Reflections on public narratives, discourse, framing, etc
    c. Reflections on speaker or audience
    d. Reflections on clinical communication
    e. Key topics and opinions beyond media discourse

Appendix 2: Interview Results – Illustrative examples of stakeholder experiences

Table 1 – Support for people with FASD and their families

Subcode 1	Subcode 2	Scope	Group	Examples
Supportive Includes support for people with FASD, their families, birth mothers, and women who drink while pregnant.	Individuals	Accounts of individuals who provide support (e.g., teachers, parents, doctors, lawyers, friends) Includes examples of specific people providing specific support, as well as broader examples of who might help, or what support looks like.	PWFASD	01-01-25: “For me, I luckily have my dad, who like, whatever I want to do, he’ll help me to do it, which is really good because he never mentions anything negative about it. He only, whenever people talk to him, mentions the good things that [I’ve] done and not, ‘Oh, well, she struggled in this,’ and if it is like a struggle, he’ll help you figure out a way to, like, make it a positive”.
			CG	02-02-15: “…there’s always been this occasional person who can reach her… her teacher in Grade 2, she flourished in Grade 2, flourished. She was speaking in front of the class and she was reading, and she was doing all kinds of things she had never done before and then Grade 3, she just went right back because it was a different teacher”.
			HCAP	03-02-21: “[A psychologist] told a story of a youth who had been referred to him by the police because he kept stealing cars, and he kept stealing, not expensive cars or anything that he wanted to resell, but he just… He could do just about everything to fix a car. He loved car engines, so he’d take the car, and he’d work on it… [the psychologist] said to the police, ‘Listen, this young man knows a lot about stealing cars, so why don’t you use him as a consultant to do resource on you stealing cars’”.
	Institutions	Accounts of institutions that provide support. Includes systems (e.g., healthcare), and other entities (e.g., businesses, society). Overlaps with *Individuals* where agents enact institutional policies or goals.	PWFASD	01-04-62: “…excited that it’s being acknowledged, especially in like education, like public education, for other people growing up with issues that I had, you know, when I was in school… that was trouble for me, and I was just the weirdo. But now, there’s kids who will grow up with the help that they need or the understanding that I didn’t have…. I wish I would have known that 20 years ago. It’s cool to see that stuff’s happening”.
			CG	02-02-12: “And after that the courts were way more lenient on her because I had been telling them for months that… this is why she cannot do court, this is why she can’t sign bail orders, this is why she can’t do conditions. After that, she was out because I think they finally just realized nobody who isn’t FASD would do this. Like it just wouldn’t occur to them to do that”.
			HCAP	03-02-21: “…we had money from the Public Health Agency of Canada to sponsor a respite camp… that was probably one of the most incredible experiences I’d ever had as a social worker”
Unsupportive	Individuals	Accounts of individuals who do not support (or who fail, ignore, or hinder). Often concretely, some abstractly.	PWFASD	01-02-51: “I was nine I found out [I had FASD]... my foster mum was telling me... no one’s ever going to want to marry you, you’re never allowed to have kids, nobody’s wanting to take care of you because you’re like a child. So, it just, it drove me kind of crazy, and then I started resenting myself and resenting her... So, it just felt really hard, and I got more angry… because nobody was there to actually help me figure it out. They just kept putting me down and telling me I was stupid. So, yeah, sorry”.

				01-04-60: “I broke down and I had an anxiety attack, and actually had one of the higher ups stand over me and laugh at me because they didn’t know…. Which after you have that happen, it really puts you off. You really, really don’t want to get up and go to work. You really don’t want to have to go look that person in the face and say you…well, you know, I had an issue, and instead of helping me, you just made it worse”.
			CG	02-02-15: “No one understood. They segregated him… He was raised in a birth home where he was… locked in a room. [The teacher] did the same thing to him. They would lock him in a rubber room. They lined it with the mats and let him scream for up to an hour until mom could get there to calm him”.
			HCAP	03-02-21: “…when they took [their child] to the emergency… The staff in the department didn’t know that the child was adopted… I think they let them know that the child was FASD, their attitude was awful, and as soon as the adoptive parents said, ‘You know, our child is adopted 100 percent’, a 360 change into, ‘Oh, well, so you’re not the parents who caused this’.
	Institutions	Accounts of institutions that do not provide support (who fail, ignore, or hinder).	PWFASD	01-02-51 (BM): “So, I couldn’t, like, there’s nothing I could do because this was court-ordered. If I left, he would have hurt my child, and that’s all I could think about. So, I’m like, you know what, I’m just going to drown everything I’m feeling right now and stay here because I can’t protect them if I’m not there”.
			CG	02-02-16: “...it is almost like there is these levels of hierarchy between the… school board and then the administration, and then the teachers. So even if one of those levels sort of understands what you are saying, there is one of the other levels that don’t…”
			HCAP	03-01-01: “…we often talk about assessment and diagnostic clinics and it makes it sound like there is a period at the end of that sentence. You assess, you diagnose and then you are done. And I really think that it should be assessment for intervention clinics…. if we fail to provide those interventions then do we run the risk of more harm? Like what are we doing and putting these families through this and then leaving them high and dry?”
Concerns about a lack of support or a need for more support		Calls for more support, for both people with FASD and women who drink while pregnant. Can include discussions about a lack of support, or questions about when or where support can or cannot be found. Includes some costs and burdens associated with a lack of formal support.		01-03-55: “Yeah. So, and I never got…like, no proper help, picked on even by [my mom], by teachers, by students”. 02-01-07: “And then not being supported throughout their lives too, that’s why they turned to drugs and alcohol because they didn’t get that support and a loving family and everything…”. 02-02-12: “It is entirely preventable should no woman drink while she is pregnant, right? But that is kind of a huge thing to ask in a society that is alcohol-based… while there is violence in families, while there are addictions, while there is no supports for those things, or very few supports… it puts a whole lot of pressure on a very small percentage of people, which are the women who are pregnant. It’s asking a lot of them”.

Interventions	Discussions about interventions, including broad calls for early intervention and examples of specific interventions. Includes discussions about effectiveness, appropriateness, existence, etc.	01-02-49: "…but it's not like you can take a painkiller or a magic pill to make your brain work. It's not just some magic pill…". 02-01-06: "My son now has a safety plan because… the first two weeks of school he got into three fistfights because he thought people were mocking him and different things, and now that the support is in place and they are doing it because it is in the safety plan, his behaviours have changed so it's okay, but he is still a danger and we can't get rid of this safety plan… '[he'll] just go around beating people up'. They are not making the connection, no matter how much you tell them, that no, he has the support he needs and that's what's making all the difference in the world". 03-01-03: "There is a big literature about showing that kids with FASD present ADHD-like, they don't have real ADHD but they are medicated for ADHD. They don't tolerate the medications for ADHD… [physicians] say 'we don't believe it, but we have to give it because everybody is expecting us to prescribe'".

Observations – Support for people with FASD and their families

Most examples coded in *Supportive* or *Unsupportive* were clear: Participants reported on their experiences with the *Individuals* or *Institutions* they felt provided, failed to provide, or hindered people with FASD, their families, or women who drink while pregnant – both in theory and in practice. However, since distinctions between *Individuals* and *Institutions* were not raised by participants (i.e., they were identified in our analysis), we also identified overlapping cases. For example, "the police" can be a branch of the criminal justice system (*Institutions*) and refer to a small group of officers (*Individuals*). Additionally, when describing problems in school, some caregivers presented a specific teacher or administrator as a key barrier (*Individuals*), connected to challenges with administrators, teachers, and 'the school' broadly (*Institutions*). In such cases, the example was coded in both the *Individuals* and *Institutions* subcode.

Interestingly, all caregiver groups discussed education as a central unsupportive institution (although social services, criminal justice, and healthcare were all similarly raised). It is striking, given that we did not explicitly ask participants about their experience in education.

Table 2 – The diagnostic process

Subcodes			Scope	Example
PWFASD experience	Self-reported	Diagnostic Journey	PWFASD self-reports about any part of the diagnostic process – when, where, how (socially, medically), other diagnoses along the way, etc.	01-03-54: “I guess growing up, I always felt like something was wrong with me, and in school I always felt stupid, not knowing what’s going on, why I can’t learn, why am I different. And in my teenage years, I got assessed… I asked… my mum about it. She denies it: ‘I never drank with you’. So, it’s even harder with your parent in denial… I don’t know”. 01-04-61: “I was in an AA meeting when I realized the symptoms. They were explaining the symptoms, and it all described me, right? And I thought, whoa… It came to realization why I was so slow in school… hard to learn”.
		Reactions to diagnosis	PWFASD self-reports of how they reacted to the possibility of an FASD diagnosis. Includes changing feelings (e.g., from denial to acceptance) and static knowledge (e.g., always known). Includes experiences without an official diagnosis (i.e., reacting to the possibility alone prior to or despite not having a diagnosis).	01-01-24: “…it kind of was normal because I was diagnosed with so many things… it’s just another diagnosis”. 01-01-25: “I was in denial at first about it. I was like, ‘Hell no! What the heck is this?’ And I didn’t even understand it at all… [only recently] I was… more accepting of it”. 01-03-54: “It’s been hard, a lot of new emotions because I’m kind of pissed off at my parents, my mum [sounds upset]”. 01-04-60: “…it was a relief because I actually knew, I finally knew, that there was something wrong, and it wasn’t just all in my head. I didn’t have people telling me that, ‘Oh, you’re just lazy or just don’t know how to do the whole life thing…’”
	CG-reported	PWFASD diagnostic journey	CG accounts of their children’s diagnostic journey, as opposed to their own journey with diagnosis (which overlap here).	02-02-16: “...he started doing all this running away thing, and he came back and started asking for help, but by the time he came back he was an adult… they don’t count anymore…”
		PWFASD reactions to diagnosis	CG accounts of how their child with FASD reacted to a possible diagnosis. Also overlaps heavily with CGs’ own reactions.	02-04-48: “…he did really well in several of the trade areas, and he got awards for them. So, very positive reinforcement. But it also made him think he’s normal. And so, he will not accept that he has any disability, except maybe writing”.
		PWFASD-directed diagnosis	CG accounts of a PWFASD who pushes for their own diagnosis, often without health professional support. We did not find any PWFASD self-reports of this.	02-01-07: “So it wasn’t until he was 18 and wanted to qualify for [disability assistance] that that gave him the incentive”.
	HCAP-reported	PWFASD diagnostic journey	HCAP accounts of PWFASD journey. Can be difficult to tell apart from CG or BM journeys (reported by HCAPs), so when ambiguous, we coded in all.	03-01-04: “I would agree that…first of all we see children in a diagnostic setting very late in the process and they have gone through many other evaluations, been given other diagnoses, the story… the journey has been very confusing…”
		PWFASD reactions to diagnosis	HCAP accounts of their patient or client’s reactions. Much easier to distinguish from BM or CG	03-01-04: “…[when] they come to see a subspecialty clinical setting… it actually does come as a relief”.

			reactions, as HCAPs typically specified who is reacting. Again, when ambiguous, coded in all.	03-02-19: “Yeah, I had one young man who was told and then ran away. We later got a call from his mother saying he was banging at her door, yelling at the door and screaming at her saying, ‘This is your fault. This is your fault’”. 03-02-19: “They already have ADHD, ODD, this and that, and they’re like, ‘No, enough. I already have this, this, this…’
		PWFASD-directed diagnosis	HCAP account of PWFASD who push for their own diagnosis (usually with or at the HCAP participant, though not always).	03-04-38: “So he like almost begged us to find out if he had FASD. So he came in, he was like, ‘I want to go see the doctor. Like, I just need some clarity’. So, he sort of asked us”.
Birth mom and family experience	HCAP-reported	BM or BF diagnostic journey	HCAP-reports of birth mother or birth involvement in diagnosis. No similar accounts found in CG or PWFASD groups. Excludes CG accounts of their diagnostic journeys connected to birth mom or family experiences (e.g., a CG gaining access to a birth mom for the sake of diagnosis). Includes accounts of birth moms who may be going on a journey toward their own diagnosis (linked to intergenerational considerations).	03-01-05: “I’m sure lots of moms go home and they are never caught because how would we know? We won’t know unless someone reports, but if someone reports, usually because they are hammered when they are going to the hospital, they know they are caught and there is a part of them that want to help the baby so they tell us like ‘look, I drank the whole time…’” 03-04-39: “…we knew that mum had developmental delays… I think it’s because she herself had FASD…. so we ended up getting her diagnosis, but largely because she understood that it might come with increased money, she might be eligible for [public disability assistance] if she got the diagnosis of FASD. That’s the only reason she agreed to be diagnosed”.
		BM or BF reactions to diagnosis	HCAP accounts of BM or BF reactions to diagnosis, where they are directly involved in the diagnostic assessment process.	03-01-03: “So one third of the birth parents are quite critical about the diagnosis and are opposing to it”. 03-02-20: “…she feels really guilty. You know, ‘My kid is different because of me’. There’s a whole stigma attached to FASD, real stigma, a real stigma, you know, about a mother. So you have to be really delicate. But I’ve found, you know, if you’ve done it in a respectful way, it really helps people”. 03-03-32: “And there have been times when clients have felt, like, a big sense of relief, but have also broken down in big tears, feeling really anxious about…how much exposure their baby had and what that really means for the child.”.
CG experience	CG-reported	Diagnostic journey	CG accounts of their experience with any aspect of the diagnostic process (distinct from accounts of their child’s journey, though they do overlap). Often accounts of seeking answers for or about their child, or for themselves, even when the child has little interest or may be in denial.	02-01-11: “I never… We never got a diagnosis. I act as if I have, we have, but we never felt the need for a diagnosis. I always just knew because we knew there was alcohol in pregnancy and I informed myself about FASD”. 02-02-14: “I adopted him when he was three… we have been living [overseas] the last 10 years… I think they don’t believe actually that mental health is even something that exists... and of course FASD doesn’t exist [overseas]. So, they didn’t believe when I said… I think he might have FASD. ‘No, no, he’s autistic or no, no, he is, you know, got attachment disorders, or anything’. They gave me all kinds of things. So we are back… We went to [a local hospital] and of course they did absolutely nothing and…. he is aboriginal, my son…”

		Reactions to diagnosis	CG accounts of how they reacted or react to their child's diagnosis. Includes changing feelings (e.g., from denial to acceptance) and static knowledge (e.g., always known). Often overlaps with the *Understanding* code, reflecting how diagnosis can slowly lead to different kinds of epiphanies about their child, sometimes around the impact of brain trauma or damage.	02-04-46: "I think I was happy to know what was wrong… until I realized that, oh, my God, I'm going to be parenting him forever… I went home and opened up the computer and read it, and then I went, 'Crap, like, this is forever'… Stunned…" 02-02-12: "…she was exhibiting all kinds of very odd behaviours… and the teacher was going 'we don't know what to do with her…' So I just felt relief because I realized, okay, this is the reality of her life and it is brain trauma, right, it's organic brain damage. This is not because she is willfully doing the stuff or she is just totally out of control all the time and she just can't handle stuff. This is something that she has to live with… and I just went from there..."
		CG-directed diagnosis	CG self-reports of pushing for diagnosis, or accounts including how they discovered their child might have FASD, often without support. Much more common than PWFASD-directed.	02-01-09: "I would say that if the parent isn't aware of FASD, good luck getting a diagnosis, because we are the ones that do all the groundwork and get all the documentation… what we need to get a diagnosis in the first place, but I would never go to a doctor and say "what's wrong with my kid" because I know there would be no way they would figure it out".
	HCAP-reported	CG diagnostic journey	HCAP accounts of CG journeys through diagnosis. Difficult to tease apart from accounts of BMs or BFs (i.e., language used often vague when describing 'parents' or 'family').	03-02-19: "So even before, we get to the diagnosis stage, I'm working with my foster parents that we're going with a suspected FASD diagnosis, and you're going to do this, this, and this, and if they don't have FASD, that's fine. Change it after, or don't. And if they do have FASD, the strategies that you're using now are going to be very beneficial".
		CG reactions to diagnosis	HCAP accounts of CG reactions to their child's diagnosis.	03-01-01: "I think reactions are always mixed for families because there is so much grief associated with anything that causes your child any kind of challenge, but I also think that sometimes families feel sort of validated in what they hear generally speaking there is some relief and there is some sense that okay, now we have a direction to go in. Not always, but I would say that is probably the most frequent reaction in addition to, like I said, the emotional reactions of course…" 03-04-36: "…a lot of the families that I've seen have been adoptive parents, and so there's not that shame or guilt. I mean, sometimes there's that grief and loss of, you know, 'I thought I was going to have a child who was going to be like this… be independent at some point'. So that's been difficult".
HCAP experience	HCAP-reported	Reactions to diagnosis	Rare cases of HCAPs discussing how it felt getting a diagnosis for a client or learning about one.	03-02-20: "…we finally knew what was happening. I think we were in the dark, and we were trying everything. Placements were breaking down… we didn't know what to do. Finally, we knew what to do… we could accommodate this… It also helped the workers move on… understand a little bit more".
		Decisions about diagnosis	Rare cases of HCAPs discussing experiences of or considerations tied to making a decision about whether or not to diagnose someone with FASD.	03-01-04: "…there are many, many other factors which you need to weigh in, and so is not just like you make a diagnosis and that's it. In fact, the diagnosis is often very… 'confounded' is the right word, but it is confused by multiple other factors like mental health during pregnancy… which is presumably the reason that she may be drinking in the first place".

Table 3 – Disclosure, understanding, and usefulness of a diagnosis

Subcodes			Scope	Example
Disclosure	Decisions	PWFASD decisions	Accounts of how, when, and why PWFASD choose or choose not to disclose an FASD diagnosis. Accounts from all participant groups.	01-04-62: “I’ve learned that there’s, like, a certain level of trust that you would kind of have to have between people. You know, not just… ‘Hey, dude! I have FASD!’ He’s like, ‘Welcome to Walmart’. [Laughter]… it’s not something you throw out there. It’s not a hat that you have that everyone can see. But… it was important for me to tell a couple of the people at school… [For] others, it’s not their business, or it’s not beneficial for me to just go spouting out everywhere… it’s a matter of trust and who you want to tell and who you want to know or if someone is able to help you or you’re able to help someone else”.
		CG or BM decisions	Accounts of how, when, and why CGs or BMs choose or choose not to disclose an FASD diagnosis. Accounts from all participant groups. CG decisions include disclosure of their child’s adoption. BM decisions include disclosure of drinking while pregnant.	02-02-12: “Inevitably somebody would ask me ‘did you adopt her?’ And I would say ‘why do you need to know?’ because they needed to know if I was the one with the drinking problem, right [some other participants sigh]? And it was very interesting. I had one lady come up to me and she said ‘you know what? I admire you so much because I think if I had a daughter like that, the first thing I would tell everybody is I was an adoptive parent’ [Laughter] because of that stereotyping. It is because this idea of ‘how could you do that to your child’, right? 03-03-28: “…when I hear that from a mum, or a mum discloses either using substances during pregnancy or a diagnosis, that’s where my brain goes, is how can I best support you”?
		HCAP decisions about disclosure	HCAP decisions to disclose: 1) a client’s diagnosis to a school; or 2) their profession. Excludes telling a patient or family, which is coded in Reaction subcodes in Table 2; this is about how others react.	03-04-39: “I’m sometimes reluctant to let teachers know if a student has a diagnosis… I can’t expect them to be trained and have a lot of knowledge about FASD, that’s not their area. But I worry that they will make an assumption about the child”. 03-03-32: “…I’m now starting to tailor what I say. So, I will say I’m a counsellor. I work with women… when I have said I’m an addictions counsellor… specifically working with mothers who are pregnant or parenting and who are working through their recovery, [others]… have made very alarming statements”.
	Consequences	PWFASD Consequences	Descriptions of how others react to their disclosure, or broad consequences like gaining supportive allies or experiences of discrimination.	01-01-22: “And they don’t really discriminate… they ask me what it’s like and what it is. And I explain it. So, it goes back and forth. When you’re younger, I don’t think it’s a good thing to bring up, but when you’re older, it’s life, so” 01-04-60: “‘FASD? Like, what’s that?’ And then, it comes on the dirty looks and… that look of just utter disgust, you know: ‘You have a disability; you’re not part of normal society’. 01-04-62: “And then, there’s people in my life… they’re a little… condescending and sort of pandering to, like, ‘Oh, well, that’s okay, you’re different’ and talk to you like you’re five years old… it happens all the time… I’ve had friends even who are nurses… they kind of turn on the nurse in their brain, and all of a sudden, I’m a patient, and they’re talking to me like I’m a nice little kid: ‘Here you go…’ Like I’m a puppy”.

		CG or BM Consequences	CG consequences can relate to disclosure of a child's adoption, BM consequences can include for disclosure of drinking while pregnant.	02-01-06: "My experience is whenever we go to a professional or a teacher or anything and I start to explain 'my [child] has FASD', the almost automatic response across the board is 'when did you adopt him?' Why do you assume he is adopted?" 02-03-40: "I wind up with a child with FASD, and I lose everything. Everybody. Nobody wants to deal with it. They know…once they realize it's life-long, that's it". 02-04-45: "People that knew were more accepting, and my family's been pretty good about it, too. The neighbours…"
Understanding	Gateway to PWFASD understanding themselves		Any stakeholder's experience with FASD helping them better understand themselves, their kids, or their clients. Often tied to framing FASD as permanent / a brain injury, or as the destination of the diagnostic journey. For BMs, can mean coming to terms with guilt or shame.	01-01-23: "All the other labels were just, like, labels… this is really what happened… a birth defect… it happened, and this is now. It made me more understanding about what my symptoms are and where they came from". 03-02-20: "'This is what's happened… I'm not bad. I'm not crazy. I've got this disability. My brain doesn't work like other people's brains. But that's okay'…we can accommodate… In my experience, it's given them a sense that there's hope" 01-04-62: "When I learned more about myself, and I go, wow, that's totally…I wish I would have known that 20 years ago".
	Gateway to CGs and BMs understanding their child(ren) or themselves. Can also include accounts of PWFASD who gain an understanding of their BM.			02-02-13: "...it was the awareness of what's down the line, that this is it. This is the rest of his life and the impact that has on me. This isn't going to go away". 02-02-46: "[My grandson] had problems from the time he was young… when you look back at it, and you put it all together, it makes sense". 01-02-49: "…my mum does wish she knew about it because it would have changed what she did… having that communication with my mother has helped because she's told me, you know, 'I feel like I broke you, it's my fault'… 'I feel like I've damaged you…' [she] feels horrible… but I don't see it as that I'm damaged. I see it more as that I just learn differently".
	Gateway to HCAPs understanding their patient/clients or families			03-01-05: "…we have kids in care, for many years we didn't know what to do, but I remember when I was [younger], a worker came in one day to a team meeting and said 'oh my God, there is this thing called fetal alcohol.' And we all went 'oh my God, that's our kids' because all the behaviour that you see and all the difficulty managing their behaviour in care, that kind of thing, it just really explained it. So we set out on a course… of really focusing on identifying these kids…"
Usefulness			Diagnosis described as useful or useless; projected as hoping it will be useful or how it ought to be useful.	01-01-24: "I can have more support from, say, the government" 02-04-48: "I… remember them sitting us down and saying, 'So… what are your expectations once you have a diagnosis?'… 'Our understanding is there aren't any services available'…. "You're right… here's your piece of paper"

Observations – Reactions to diagnosis

I included these tables at the end of my thesis to reflect on the theme of "reactions to diagnosis." When we designed this study, we built our questions on themes we identified in our media analysis and Link and Phelan's model of stigma. We wanted to understand how two of the five elements of their model (labelling difference and stereotyping) would be felt by participants in the context of FASD, alcohol, and pregnancy. Although we published the results associated with stereotypes, we did not publish material about reactions to diagnosis – which reflect the "labelling difference" component of their model. Table 2 includes stakeholder accounts of their reactions to their lived experience of an FASD diagnosis, which reflect elements of self-stigma and stigma toward birth mothers. Table 3 includes stakeholder accounts of reactions of others in the world around them. In Table 2, participants in all groups reported a wide array of reactions to a possible FASD diagnosis: relief, to finally have an answer; anger, at birth moms for consuming alcohol; denial that anything has happened; guilt as a birth mother for having consumed alcohol; grief, at realizing the challenges that lie ahead; and as just another diagnosis along a diagnostic journey, or as one too many. In Table 3, participants reported a different set of reactions from others: confusion and a lack of understanding; disgust or rejection; as well as increased support.

Importantly, as I addressed in Chapter 5, a central tension in understanding participant accounts arose when considering how to tease apart themes related to FASD from themes tied to disability broadly. For example, I did not name a code 'Challenging experiences with FASD' (i.e., FASD as cause of challenges); instead, I used a broader code to reflect this concern called 'Challenging Experiences' (i.e., FASD perhaps correlated with challenges). Similarly, when listening to participant accounts of reactions to their diagnosis, some of these reactions have more to do with ableism broadly than attitudes about FASD, alcohol, and pregnancy specifically.