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

John Aspler [a,b], Aline Bogossian [a,c] and Eric Racine[a,d,e]

aPragmatic Health Ethics Research Unit, Institut de recherches cliniques de Montréal, Montréal, Canada; bIntegrated Program in Neuroscience, McGill University, Montréal, Canada; cSchool of Social Work, Université de Montréal, Montréal, Canada; dDepartment of Medicine; Social and Preventive Medicine, Université de Montréal, Montréal, Canada; eDepartment of Neurology and Neurosurgery; Experimental Medicine, McGill University, Montréal, Canada

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.

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).

Conceptualising 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 disabilities). 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; (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).

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

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 generalised … 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 a lot of the 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, I think 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 internalise 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).

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

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

Alcohol and pregnancy stereotypes	Illustrative examples of alcohol and pregnancy stereotypes
Demographic expectations: Assumptions 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).

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).

Differences in stereotypes of interest 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

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)

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 marginalised 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 marginalised 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.

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 of its elements through our participants' experiences and concerns. (For more on the operationalisation of theoretical concepts through qualitative inquiry, please see work in pragmatic bioethics: (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.

Notes

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."

ORCID

John Aspler 🔾 http://orcid.org/0000-0001-7055-4357
Aline Bogossian 🔾 http://orcid.org/0000-0002-9816-5887

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