Fetal Alcohol Spectrum Disorder
In Context

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Executive Summary

Introduction

FASD’s historical, sociocultural and political contexts are often overlooked. However, available research suggests that consideration of these factors may play an important role in developing increasingly valid and reliable FASD-related policy and practice standards.

Purpose

The present project was conducted to develop clearly defined research questions to guide future research on FASD. Specifically, the goal was to define questions that were 1) grounded in available literature that considers FASD’s historical, sociocultural and political contexts 2) well-positioned to inform FASD-related policy and practice standards in British Columbia 3) maintain a manageable scope.

Methodology

A rapid literature review methodology was employed in the present report.

Literature Review

FASD research, which has predominantly been conducted from a biomedical perspective, has rapidly grown in popularity over the past 50 years. While considerable advancements in understanding about the impacts of prenatal exposure to alcohol have been made in this time, significant gaps in understanding remain. These gaps impact the reliability and validity of current diagnostic guidelines, which themselves are limited by their focus on ascribing cause. Implications are found in popular public health messaging about maternal drinking which have often focused on individualizing the problem by placing blame on mothers. In doing so, these messages shift attention away from relevant sociocultural and political forces.

Indigenous peoples in Canada face stereotypes related to drinking and FASD. While these stereotypes suggest that Indigenous mothers consume more alcohol than non-Indigenous peoples, evidence indicates the opposite. The consequences of these stereotypes include the possibility of pervasive discrimination in healthcare systems and the misdiagnosis of FASD among Indigenous children.

Recommendations

1. Conduct future research to consider best practices that address FASD-related stereotypes and culturally sensitive approaches to diagnostic screening.

2. Investigating possible irregularities in existing FASD-related research.
Introduction

This report presents Fetal Alcohol Spectrum Disorder (FASD) in a historical, biomedical, sociocultural and political context. By doing so, it seeks to illuminate perspectives related to FASD that are often overlooked or silenced. This report was conducted in an effort to establish research questions to guide future inquiry that align with calls to develop FASD-related policy and practice standards that are increasingly socioculturally and contextually focused (see Hankivsky et al., 2014; Hunting, Grace & Hankivsky, 2015). To do so this report draws on relevant literature from Canadian and international sources, however, recommendations are made to specifically support further insights into FASD within a Canadian context.

Rationale and Purpose

As of 2017, there were 37,800 cases of FASD in Canada (Lange et al., 2017). The estimated cost of FASD to Canadian society is $1.8 billion dollars annually. While the majority of academic research related to FASD, which directly informs practice and policy, is situated within a biomedical model, relatively little consideration has been given to the historical and sociocultural context from which FASD emerged and continues to be effected by. Further, anecdotal accounts suggest that the assignment of an FASD diagnosis may in part be related to stereotypes rather than objective assessments.

The present research presents a brief literature review of the historical, sociocultural and political contexts in which FASD is currently situated, in addition to challenges that have recently been made to its diagnostic criteria on logical grounds. Clearly defined research questions to guide future consideration of FASD’s complex and consequential nature in Canada emerge from this literature review.

Research Questions

What future considerations will support the development of increasingly socioculturally and contextually focused FASD-related policies and practices in British Columbia?

What research questions may support culturally sensitive practices and policies associated with FASD in British Columbia?
Methodology

A modified version of Wickremasinghe, Kuruvilla, Mays and Avan’s (2015) rapid literature review was employed in the present report. Rapid reviews are appropriate when addressing research questions that are constrained by time and are aimed at “finding key-issues on certain topics which may provide new research questions for more in-depth literature reviews” (Jansen, 2017, p. 17; also see Abrami et al., 2010). The focus of a rapid review is to synthesize and review key pieces of literature associated with the particular topic(s) in question, rather than perform a systematic review of all available research (Grant & Booth, 2009; Wickremasinghe et al., 2015). The resulting synthesis and review is presented through a narrative report that outlines key findings that inform the proposed research questions for future considerations (Wickremasinghe et al., 2015). This approach was well-suited to the current project, reflecting its purpose and associated time-constraints.

Key pieces of literature associated with the historical, biomedical, sociocultural and political context of FASD were identified using relevant search terms. The present report’s sponsor also supported this process. Finally, the literature search employed a snowball technique to identify further documents from the retrieved references. A snowball technique involves reviewing the reference sections of identified literature, as well as literature that has been cited in the already identified research, to find additional resources (Abrami et al., 2010).

Once identified, the retrieved literature was reviewed and synthesized by the two graduate student researchers associated with this project. This process was supported though consultation with the project’s sponsor. The aim of this synthesis was to identify key themes associated with the research topics and assess how these themes may inform future research questions that in turn could inform policy and practice. A summary of the synthesized literature is outlined in the present report, as well as the resulting recommendations for future research.

Rapid review approaches face certain limitations. Accelerating the data extraction process may lead to missing relevant information associated with the research topic as the literature selection process is unsystematic and time constrained (Ganann, Ciliska, & Thomas, 2010; Grant & Booth, 2009). Further, this approach is prone to selection and publication bias as it relies on gathering relatively easily accessible and available literature (Ganann, Ciliska, & Thomas, 2010; Wickremasinghe et al., 2015). Despite these limitations, a rapid review methodology was an appropriate approach to address the current research questions and the project’s time constraints.
Literature Review

Research stresses the need to contextualize conditions surrounding FASD diagnoses, including social, cultural, political, and historical factors which inform the diagnosis, incidence, and experiences of FASD (Salmon, 2005). The present report seeks to do just this by reviewing available literature. First, the historical emergence of FASD is traced, and gaps in the current of the effects of embryonic exposure to alcohol are briefly presented. Then, dominant public health messaging and challenges associated with FASD’s diagnostic criteria in Canada are presented. Finally, the present report reviews evidence illustrating how these gaps and limitations are situated within Canada’s sociocultural and political context, with a specific focus on the impact they have on Indigenous communities and mothers.

Tracing the Biomedical Emergence of FASD

Maternal drinking and ‘disordered’ health outcomes for children have a complicated and storied history. Anecdotal accounts of alcohol prohibition during pregnancy date back to ancient Greek and Roman eras, and written reference to the detrimental effects of prenatal exposure to alcohol can be found in Aristotle’s writings as well as the Bible (Calhoun & Warren 2007; Riley, Infante, & Warren, 2011).

It is often cited that popular academic consideration of the effects of embryonic alcohol exposure, which has widely been conducted through a biomedical lens, was first stimulated by Dr. William Sullivan (Able, 1997). In his 1899 paper ‘A Note on the Influence of Maternal Inebriety on the Offspring’, Sullivan reported that stillborn birth rates were higher among female prisoners who presented with alcohol dependent behaviours (Calhoun & Warren, 2007). This research went against popular scientific opinion as at the time, environmental factors were not widely considered as variables that could impact health (Calhoun & Warren, 2007).

Further scientific consideration of maternal drinking’s impact on fetal development was not made for over 70 years. Three papers published in the British Medical Journal, The Lancet (Jones et al., 1973; Jones and Smith, 1973; Jones et al., 1974), changed this. These papers, written by two dysmorphologists, Jones and Smith, at the University of Washington’s School of Medicine in Seattle, presented descriptive case reports that outlined the association between maternal drinking and a host of common facial features and challenges associated with cognitive functioning and behaviour (Riley, Infante, & Warren, 2011). These authors suggested that their data were “sufficient to establish that maternal alcoholism can cause serious aberrant fetal development” (Jones & Smith, 1973, p.1269), and introduced the term Fetal Alcohol Syndrome (FAS).

Following the publication of Smith and Jones’ findings, research on the physical, behavioral, and cognitive effects of prenatal alcohol exposure rapidly proliferated, further reifying FAS (Price-Green, 2006). This research was predominantly biomedical in nature and started to receive funding from government organizations throughout the 1970’s-1980’s in an effort to decrease maternal consumption of alcohol, particularly in the United States (Armstrong & Able, 2000). As evidence illustrating the relationship between maternal drinking and disconcerting childhood development outcomes increased, a moral panic was sparked that began shifting attention away from social inequalities, such as socioeconomic circumstance, and towards blaming
pregnancy outcomes on individual mothers (Armstrong & Abel, 2000; Salmon, 2004, 2005). By the 1990’s, maternal drinking was seen as a major public health concern (Armstrong & Able, 2000; Egeland et al., 1998; Stratton et al., 1996).

While FAS was first used in the 1970s to describe a cluster of birth defects due to prenatal exposure to alcohol, the term FASD has since been adopted in Canada. FASD is an umbrella diagnostic term that describes “a broader spectrum of presentations and disabilities resulting from alcohol exposure in utero” (Cook et al., 2015, p. 1). FASD includes the diagnoses FAS, partial Fetal Alcohol Syndrome (pFAS), and Alcohol Related Neurodevelopmental Disorder (ARND) (Cook et al., 2015).

In the time since Jones and Smith’s first account of FAS, notable advancements in the biomedical understanding of the effects of prenatal exposure to alcohol have been made. However, this research has several limitations. For example, it has largely been undertaken in a manner that seeks to illustrate a causal relationship between maternal drinking and resulting physical and neurodevelopmental symptoms (May, Blankenship, et al., 2013; Price & Miskelly, 2015). Further, the amount of exposure to alcohol needed to produce developmental impairments is still not well understood (Riley, Infante, & Warren, 2011). These limitations alone present challenges for reliable and accurate diagnoses. The present literature review now turns to the sociocultural factors within which these limitations are embedded to consider how they may unequally impact the application of diagnostic criteria among marginalized groups in Canada.

Public Health Messaging and Diagnostic Guidelines

While Canadian public health messages currently claim that all levels of alcohol are dangerous to the developing fetus, there is an absence of evidence to support this (Tait, 2008). Illustrating this discrepancy, it is estimated that one in sixty-seven mothers who consume alcohol during pregnancy in Canada will have a child with an FASD diagnosis (Armstrong & Able, 2017). Further, attitudes towards safe levels of alcohol consumption during pregnancy vary widely from country to country without any empirical relation to FASD (Pacey, 2010; Salmon, 2008).

A parallel discrepancy can be found in FASD’s diagnostic guidelines, which have been suggested to be insufficiently specific to assure accuracy (Tait, 2003). Salmon (2004) outlines how the Canadian diagnostic criteria for FASD are highly subjective and open to misapplication. In doing so, Salmon (2004) argues for the need to address the validity and reliability of available FASD screening tools. For example, it has been suggested that the facial dysmorphism associated with FASD may be similar to those normally present in some non-EuroWestern ethnicities, such as Aboriginal, Metis and Inuit peoples in Canada, opening the door for misdiagnosis (Pacey, 2010). Further concerns about opportunities for misdiagnosis within the current Canadian guidelines have been brought up by McLennan and Braunberger (2017). These authors highlight the similarities between FASD’s behavioural and neurodevelopmental symptomatic presentations that are common to other developmental disorders such as ADHD.

Positioning alcohol consumption as a central component of FASD’s diagnostic criteria shifts attention away from other potential causal factors. It should be emphasized that neurodevelopmental impairments can result from a host of causes, not just prenatal exposure to alcohol (Price & Miskelly, 2015). As outlined above, not all women who have consumed alcohol
during pregnancy give birth to children who meet the criteria for an FASD diagnosis. Further, some women who have not consumed alcohol during pregnancy may have children with symptoms consistent with FASD criteria (Helgesson et al., 2018). Price and Miskelly (2015) add support for this, as they suggest that differentiating between brain damage caused by alcohol and brain damage caused by abuse and multiple concussions may be challenging (Price & Miskelly, 2015). Taking these points together suggests that it would be valuable if other contributing factors in FASD diagnostic criteria were given increased attention (Helgesson et al., 2018).

Significant consideration needs to be made in assuring the accuracy of an FASD diagnosis as it focuses on causation and does not offer specific treatment or intervention recommendations (McLennan & Braunberger, 2017). If cause is determined as prenatal exposure to alcohol, and it cannot be treated, then what are the consequences for diagnosis (Price & Miskelly, 2015)? This question becomes particularly relevant when acknowledging that an FASD diagnosis may create problems related to stigmatization for the family, and specifically the mother (Helgesson et al., 2018). Further, it supports the notion that the impacts of an FASD diagnosis and diagnostic accuracy should be considered before any diagnosis is made (McLennan & Braunberger, 2017).

**Alcohol-Related Stereotypes**

Indigenous peoples in Canada are often stereotypically portrayed as heavy alcohol consumers. However, current research suggests that more Indigenous peoples actually abstain from the use of alcohol than what is perceived in dominant outside perceptions of alcohol use (Statistics Canada, 1993 as cited by Tait, 2003). According to Tang and Browne (2008), dominant misconceptions about the lower socioeconomic position of Indigenous peoples in Canada, combined with stereotypes related to substance abuse issues, play a powerful role in biasing the perceptions of healthcare professionals and frontline workers. These factors can lead to misdiagnoses of FASD in Indigenous populations. For example, the disproportionate attention paid to FASD and Indigenous peoples in Canada supports a commonly-held belief that substance abuse during pregnancy occurs more frequently among Indigenous women compared to non-indigenous women (Pacey, 2010).

**Indigenous Women and Mothers**

Historically, the dominant image of Indigenous women in Canadian society can be traced to the colonial images used to disvalue their morality and skills as mothers (Browne, 2008). A tendency toward stigmatizing discourses in health policies can operate in ways that overlook the complexities of women’s social locations, contexts, health and social issues (Hunting & Browne, 2012). Put another way, placing moral responsibilities on what society may construct as unfit mothers, in this case Indigenous women in Canada, shifts the focus away from institutions and their failure to protect and support vulnerable groups (Helgesson et al., 2018). This has been illustrated by the focus on birth control methods in past FASD prevention campaigns (Tait, 2008).

Indigenous women often experience discrimination, particularly associated with their role as mothers, regarding substance abuse problems (Tait, 2003). This discrimination constructs Indigenous women as the perpetrators of the FASD problem, while the structural, social, and health inequities that give rise to women’s alcohol use remain ignored (Hunting & Browne, 2012). This
is illustrated by the fact that Indigenous mothers are more likely than non-Indigenous mothers to be screened for substance use during pregnancy (Pacey, 2010).

A common misconception in Canada is that FASD diagnostic rates are associated with ethnicity, such as higher rates among Indigenous children (Chudley et al., 2005). This depiction, along with the common constructions of Indigenous mothers as uneducated and dangerous, further perpetuates stigmatization of Indigenous women (Hunting, & Browne, 2013). Salmon (2004) argues that the presentation of alcoholism as a disease to which Indigenous peoples are particularly inclined continues to pathologize individual Indigenous mothers as objects of blame.
Discussion and Recommendations

In order to explore our research questions further a rapid literature review was conducted. This review highlighted the historical, biomedical, sociocultural and political contexts of FASD in Canada. Specific consideration was given to the disproportionate impacts of stereotypes related to drinking and FASD on Indigenous peoples, illustrating the way in which gaps in understanding may influence practice and policy within a Canadian context. As contradictions in FASD’s diagnostic criteria may undermine the accuracy of diagnoses, it becomes increasingly important to address the consequences of these limitations. By drawing on the literature reviewed here the present report proposes research questions that are well-positioned to begin addressing these limitations by informing future policy and practice. They include the following:

1. Conducting a judicial scan and/or literature review to consider
   
   1.1 What are best practices that address pervasive FASD-related stereotypes in Canada?
   
   1.2 What are FASD-related best practices that consider culturally sensitive approaches to diagnostic screening?

2. Investigating possible irregularities in existing FASD-related research when compared with other developmental diagnoses such as ADHD and Autism

   2.1 Have specific minority groups been disproportionately represented as research subjects?

   2.2 What are the popular geographic locations of FASD research in Canada?
References


