An Overview of the Current State of Fetal Alcohol Syndrome in the Canadian Region and an Analysis of Policy Discourse

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Abstract: Fetal Alcohol Syndrome (FAS) is a disease in which the central nervous system is permanently damaged by the mother's alcohol consumption during pregnancy. The paper also analyses the Public Health Agency of Canada's Fetal Alcohol Spectrum Disorders Framework for Action from the perspective of policy discourse, examining the racism behind FAS and the stigmatization of Aboriginal women, and making recommendations for future prevention and intervention.

1. Introduction

Fetal Alcohol Syndrome (FAS) is a condition that results from the mother's alcohol consumption during pregnancy. All affected children have neurodevelopmental deficits in intelligence, attention, learning, memory, visuospatial reasoning, executive function, motor function, self-regulation, language and communication, social skills and academic performance[1]. The main symptoms of fetal alcohol syndrome are developmental delays before and after birth, various abnormalities of the central nervous system, and certain characteristic abnormalities of the face and head, like the latter including microcephaly (small head), short lid fissures (small eye holes), ptosis (drooping eyelids), eyelid folds (folds of skin in the inner corners of the eyes), a short, upturned nose, a long, smooth midperson (the area between the nose and mouth), a thin upper lip and a jaw small. Abnormalities of the central nervous system can lead to mental retardation or mental retardation, as well as various behavioural problems such as inattention, impulsivity and an inability to consider the consequences of one's actions. Patients with congenital external strabismus syndrome may also have various internal organ abnormalities, including the heart. Alcohol at any level is unsafe for the developing embryo and foetus, and alcohol can cause extensive brain damage and physical abnormalities in the foetus. While the disorder can be ameliorated to some extent with the influence of modern medicine, the cognitive behavior and physical impairments in individuals can last a lifetime[2].

Exact figures for the prevalence of FAS in Canada are difficult to obtain, but according to a 1996 study, it was approximately 0.5 children affected per 1,000 newborn survivors[3]. Thus, FAS has become a problem that cannot be ignored in Canadian society. This paper presents a review of previous research and papers on fetal alcohol syndrome in Canada, identifying the impact of the disease on the lives of those affected and on Canadian society as a whole; and using existing policies as an analytical text to analyse existing prevention and treatment measures and to discuss future prevention and treatment tools from legislative and other perspectives.

2. Literature Review

An independent and comprehensive literature search of FAS-related journal articles and books published from 2003 to 2022 was conducted using several electronic databases (e.g., Google Scholar, Glasgow University Library, Web of Science). The literature was located using multiple keywords such as fetal alcohol syndrome, prenatal alcohol exposure, policy, fetal alcohol spectrum disorders, and Canada. One stream of research focuses on the prevalence of FAS, its symptoms, how it is diagnosed and other aspects that help people understand the disease (e.g., Chudley, 2005), while

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another perspective paper focuses on the consequences of FAS and how to combat it (e.g., Rasmussen et al., 2008; Tough et al., 2004). While each of these streams makes important and unique contributions to the literature on improving cognitive and problem-solving skills in FAS.

The social dilemmas faced by people with FAS and the outcomes of these dilemmas are mainly discussed in the following key literature:

Firstly, people with FAS are vulnerable to abuse. According to Roach& Bailey (2009), people with FAS are extremely eager to make friends, but they have some social deficits which lead to peers often rejecting them and even beating and abusing them.

Secondly, People with FAS are more likely to face incarceration problems than others without the disease. Burd (2003) [4] conducted a survey of 400 adolescents and adults with FAS and found that 50% were incarcerated for mental health problems, alcohol/drug problems or crime. Also, according to a 2004 survey, more than half of the 415 patients had also experienced incarceration(Roach and Bailey, 2009).

Thirdly, people with FAS confront the dilemma of drug and alcohol abuse in their lives. The available literature suggests that a disproportionate number of people with FAS have substance abuse problems in their lives. For example, in the Gtant et al. study, 68% of the women had abused alcohol prior to participating in the program. These patients abused drugs/alcohol possibly for the following reasons: biological vulnerability; these patients were using drugs for self-medication; FAS patients have difficulty controlling the urge to abuse substances due to physical deficits and life stressors[5].

Fourthly, patients may suffer the breakdown of family relationships. According to a study by the University of Washington in 2004, 80% of the 415 patients were not raised by their own mothers. This chart shows data from the study's survey of participants' family relationships. The reason for this is that every mother has some degree of alcoholism, which can lead to early death, abuse and neglect in the mother's life[6].

Fifthly, children with FAS may experience far more interruptions in schooling than other children. According to Streissguth (2004), approximately 53% of patients had been suspended from school as adolescents, 29% had been expelled, and 25% had dropped out of school. This was associated with factors such as their poor concentration and repeated failure to complete schoolwork.

3. Policy Responses

Public policy is defined as a plan, a framework, and a guide for problem solving in the process of action and inaction [7]. Policy discourse, with its specific meanings and signifiers, helps to conceal social problems and social conflicts while promoting the dissemination of the general public interest [8]. Discourse analysis of policy is thus useful in understanding the ideology of government and other interest sectors.

Gendering and colonization in policy

> *"FAS/FAE are serious concerns for First Nations and Inuit...You can prevent FAS/FAE by not drinking alcohol when pregnant or nursing."*
>
> (Health Canada,2002a)

As can be seen in the original policy article above, the Canadian FAS prevention campaign combines Aboriginal issues with those of children with FAS [9]. This has led to FAS being perceived as an Aboriginal issue in the popular perception of society. This discussion shifted the attention that should have been given to the social factors that contribute to pregnant women's drinking to a negative reading of the social issues of Aboriginal women's role in Aboriginal health and racialization[10]. Racialization is defined as the process of attributing social, economic and cultural differences to race and marginalizing individuals and groups through everyday behaviors, attitudes and institutionalized policies.

In 2005 the Public Health Agency of Canada (PHAC) released a key policy document on FAS - Fetal Alcohol Spectrum Disorders: A Framework for Action (hereinafter referred to as 'the

Framework for Action'). "The Framework for Action served as a starting point for action on FAS and was intended to provide frontline staff, policy and regulatory stakeholders with a clearer understanding of FAS and to collaborate in its implementation. A critical analysis of the policy discourse revealed three main problems with the policy.

First, individual mothers are seen as dangerous. According to Tait (2009), the dominant policy discourse in Canada ignores the context of women's lives and the complexities of their physical and mental conditions and substance use and portrays these mothers as 'indifferent to their children and society'(Hunting and Browne, 2012). This ideology has a long history, for example, Health Canada's manual on FAS states that the prevalence of aboriginal infants is greatly increased and that they are viewed as people with lifelong disabilities and considered to be an educational, economic and social concern for the country as a whole[11]. This suggests that the perception of Indigenous FAS sufferers at the national level is an increased burden on the nation as a whole, which devalues Indigenous peoples as a whole and increases the blame placed on mothers [12][13]. This ignores the injustice and discrimination experienced by Indigenous mothers in their everyday lives and instead blames FAS solely on the individual choices of mothers.

Second, the stigmatization of Indigenous women. The colonial legacy of Indigenous peoples' subordination has led to multiple dangers for Indigenous women, such as discrimination by individuals and organisational groups, and disadvantages based on race, gender and class (Browne and Fiske, 2001; Dion-Stout, 1996). There is a general negative societal attitude towards women who misuse substances, which severely affects Aboriginal women - particularly those with substance misuse problems (Poole, 2000). Consistent with the policy released by the Ministry of Health in 2002, the Framework for Action, when describing FAS, explicitly states that the problem of FAS is more severe in First Nations and Inuit communities. This explicitly ethnic descriptive discourse fails to link the health experiences and life contexts of Aboriginal women, reinforcing the single link between colonisation and FAS. In addition, Indigenous women experience many difficulties and prejudices in accessing services that make it difficult for them to access prenatal and addiction treatment services. These barriers include long waiting lists for treatment centres and women's fear of losing custody of their children at birth if they admit to needing help when they are pregnant [14].

Thirdly, the Framework for Action focuses on health education as primary prevention and treatment. Examples include 'no alcohol' [15] and adherence to 'sensible guidelines' (PHAC, 2007). These policy discourses suggest that the government believes that alcohol consumption during pregnancy is largely the result of a lack of awareness. However, raising awareness alone does not necessarily improve the problem of alcohol consumption during pregnancy. As with Marx's philosophical view, it is the potential addiction to alcohol that is the more controversial issue, and one should look beyond the phenomenon to the essence of the problem. The focus of policy should be on how to address the stresses of life experienced by pregnant women and how to improve their mental health [16][17]; the concern for Aboriginal women should be the gender and racial discrimination they experience. These are issues that cannot be addressed simply by raising awareness and providing health education. Also, to date, no approach has been adopted in the Canadian region regarding health warning labels(Kyskan and Moore, 2005). According to the Centre for Addiction and Mental Health (CAMH) (2001) [18], labelling is a cost-effective prevention tool that facilitates the provision of information to enable consumers to make informed decisions about alcohol consumption.

4. Intervention

The following existing approaches to FAS prevention and treatment have been adopted in Canada.

Firstly, recognize and prioritize the importance of alcohol use and FAS health issues during pregnancy at a societal level and provide a range of care, including assistance with withdrawal symptoms, treatment and care for pregnant women.

In 1996, Health Canada, along with other relevant governmental responsibilities, made a series of recommendations for the prevention and treatment of FAS[18]. In 2000, Health Canada provided $11 million for the implementation of a FAS prevention and treatment programme aimed at increasing public awareness, education and diagnostic recognition (Health Canada, 2000a). In addition, Health

Canada has undertaken and funded a number of projects to address prenatal and early childhood health issues. For example, the Community Action Program for Children (CAPC) includes a Break the Cycle (BTC) program, which is a systematic service for pregnant women with substance abuse problems and their children directly related to addictions and health issues. However, the range of care help also leads to an excessive financial burden. According to the Drug and Alcohol Treatment Information System, in 2010/2011, the cost per outpatient diagnosis and withdrawal service in Canada was $60-$109 and inpatient treatment cost $138-$314 per day. Using 2010 data on the population of the University of Narita and a prevalence rate of approximately 9 per 1,000, and again based on the study by Famy et al. that the proportion of substance abuse among FAS patients was 55%, the cost to Canada in 2010/11 would have been $240,000 - $5,340,000. This is undoubtedly a huge expense and would place a huge economic burden on society as a whole.

Secondly, restricting the availability and use of alcohol. According to Tait (2003), some evidence suggests that restricting the availability of alcohol, such as banning the sale and importation of alcohol or increasing prices, can alleviate the problem of alcohol abuse among pregnant women in the short term. Some Aboriginal communities in Canada have responded in this way, for example, the Northern Quebec regional government has the power to impose a 'dry period' on alcohol sales, thereby restricting the delivery of alcohol to the region from other areas. The problem, however, is that bootlegging is common in these areas where prohibition is attempted, and this can lead to an even more unchecked alcohol abuse problem.

5. Discussion

The following recommendations are available on how to combat FAS in the future.

Firstly, raise awareness about the relevance of FAS. Awareness here includes the importance that various groups and systems in society place on FAS.

The first is the incarceration system. Burd (2003) conducted a survey of the Canadian correctional system's perceptions of FAS, screening strategies for FAS, and the extent to which staff were trained in the issues involved. The findings showed that the prevalence of FAS in the correctional system ranged from 0.33 per 1,000 to 9.1 per 1,000. This figure is not exact and is an extrapolation from the prevalence in the Canadian population as a whole. Both conservative and aggressive estimates suggest that hundreds of cases go unreported. This proves firstly that the number of people with FAS in the incarceration system is not a negligible number and secondly that it is extremely important to correctly recognize and identify FAS. Furthermore, the study mentions that the level of access to services, infrastructure investment, staff awareness and diagnosis for FAS patients in the incarceration system is very low(Burd, 2003). In addition, over 50% of patients have substance abuse problems and therefore the correctional system should invest more and raise awareness and knowledge among staff.

The second is to raise women's awareness of the disease. FAS is caused by the consumption of alcohol by pregnant women during pregnancy, and any dose of alcohol is extremely dangerous for the foetus. The International Charter for the Prevention of Fetal Alcohol Syndrome mentions that there are many potential risks for women during pregnancy, such as social stress, emotional stress, etc. Pregnant women may seek help from alcohol for this reason and the lack of awareness of the disease can exacerbate the intake of alcohol during pregnancy. Thirdly, men also have an inescapable responsibility for the prevention and treatment of FAS. Johsson et al. (2014) state that partners who do not show a supportive burst rate during pregnancy and abuse alcohol, may become irritable or even use violence, adding to the stress of the pregnant woman or even asking her to share alcohol. According to Waterson (1990), a change in partner's smoking habits is the biggest contributor to pregnant women's abstinence from alcohol. Similarly, it could be expected that if society provided men with information about FAS, the number of pregnant women quitting drinking would increase.

The second intervention is improving policy. As previously mentioned, Canadian policy currently racializes and marginalizes women, and future policy development will focus on shifting the overemphasis on the individual pregnant woman to one that recognizes the impact of various social correlates and marginalization on women and children. Hankivsky et al. (2010)[18] emphasize that the

key to addressing health inequities in Canada is to focus on the intersectional approach of social, historical processes, yet in the areas of substance use and addiction there remains a significant lack of systematic analysis on gender and equity(Hunting and Browne, 2012). Thus, future policy development needs to increase analysis and research in this area in order to increase programs and interventions that support women's health. In addition, there should be a greater disconnect between policy introduction and implementation. For example, in the appendix to the Framework for Action, it is proposed that indigenous people should be at the centre of future consultations. However, there is no commitment to include input from indigenous-related sectors in future actions.

Thirdly, increasing attention to people and health issues in Aboriginal areas. Smylie (2000) offers several guiding principles for health and social service providers in Aboriginal communities. Increase knowledge of the names and characteristics of various Aboriginal groups in Canada and increase knowledge of the status of Aboriginal populations. Become familiar with cultural phenomena such as the traditional geography and language of Aboriginal peoples. Understand the negative impact of colonization on the health and well-being of Aboriginal peoples. Be aware of the discrimination faced by Aboriginal populations. Recognise the importance of supporting indigenous peoples (Tait, 2003)

To conclude, it is important to give indigenous issues a higher priority, to treat indigenous peoples equally and to avoid policy discourses that colonise and marginalise indigenous peoples in relevant policy literature.

6. Conclusion

In summary, people with Fetal Alcohol Syndrome (FAS) face physical and psychological challenges throughout their lives and all aspects of their lives can be very negatively impacted. FAS is a health issue that cannot be ignored and the prevention and treatment of people with FAS is an important part of health care in Canada. The Canadian government and authorities have enacted a number of acts and policies to address this disease, but these policy discourses demonstrate the colonization and marginalization of Canadian women. In future practice, Canada should take measures that do not simply impose responsibility on individual pregnant women, but through the awareness and efforts of society as a whole.

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