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Gap Analysis: Black Identity and Fetal Alcohol Spectrum Disorder

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KEY MESSAGES

The impact of health disparities within the Black community has been outlined in several disease processes, resulting in poorer health outcomes such as increased morbidity and mortality. However, little is known about the intersectionality of being Black with a diagnosis (or possible diagnosis) of FASD, especially within Canada. Increased research initiatives focused on identifying the prevalence and experience of FASD within the Black community, as well as culturally aware supports and resources, are required.

Issue:

Since the COVID-19 pandemic, there has been increased attention to the significant health disparities experienced by Black peoples leading to inadequate diagnoses and treatments.[1,2] For decades, attention has been paid to the social and structural determinants of health, including social, economic, political, and institutional factors, and how they shape health and contribute to health inequities.[3] Such influences, including Anti-Black racism and medical racism stemming from implicit bias and discrimination, continue to contribute to disparities in health and quality of life among Canadians, including those experienced by diverse Black peoples in Canada.[4] Medical racism targeted towards Black populations has been observed within many health conditions, including prenatal alcohol exposure (PAE) and fetal alcohol spectrum disorder (FASD).[2,5-8] The increased prevalence of FASD diagnosis within Black youth has been predominantly identified within the United States (US) and South African contexts.[9,10] However, there is a lack of research exploring the prevalence of FASD among Black communities and the experiences of those who live within the intersection of being Black with FASD in Canada.[9,10]

This gap analysis aims to highlight the limited research on the disparities in FASD diagnosis among Black peoples observed globally, and to urge further work – in Canada and internationally – to meet the needs of those who are within the intersection of being Black with FASD.

Background:

Anti-Black racism is at the core of the significant health disparities faced by Black peoples navigating the Canadian health care system.[4,11-15] Systemic and structural racism within the

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health care setting, also defined as medical racism, results in inattention to Black patients and the dismissal of Black voices and experiences, leading to poorer health outcomes, incorrect diagnoses, and inadequate resources and treatments.[4,11-16] The historic lack of race-based data in the Canadian health care system has left many gaps in understanding the specific health experiences faced by Black peoples, especially those with neurodevelopmental and behavioural diagnoses.[17]

Researchers from the US have continued to highlight the stark disparities faced by Black peoples regarding neurodevelopmental and behavioural diagnoses, such as the increased rate of diagnosis of both conduct disorder (CD) and oppositional defiant disorder (ODD) among Black youth compared to White youth.[18-22] Such diagnoses are often detrimental to these Black youth as they carry significant negative social weight, directly impacting the youth's family, their navigation of the educational system, and their operation within broader social constructs.[18-23] Additional disparities observed within neurodevelopmental and behavioural diagnoses include the decreased rate of diagnosis and management of attention-deficit/hyperactivity disorder (ADHD), delayed and reduced autism diagnosis, and delayed referral to mental health services among Black communities compared to White communities.[18-22,24]

With such pervasive health disparities already noted with respect to neurodevelopmental diagnoses among Black youth, and with consideration of the health and social inequities linked to discrimination at multiple levels of society (i.e., individual, interpersonal, institutional, and societal) among Black Canadians,[4] there is a need for further investigation of how these disparities and the social and structural determinants of health have impacted the intersections of PAE and FASD diagnosis.

What Do We Know About Being Black with FASD?

Dr. Carl Bell once said that FASD is the "biggest public health problem for African Americans since slavery."[25] Although this quote emphasizes a disheartening message, it also highlights that with targeted research towards identifying trends within the prevalence of FASD, clear disparities have been identified, with Black peoples being disproportionately affected. However, there is currently limited research and data that address the experiences of Black peoples in Canada with PAE or FASD. Broadening the scope of understanding to include data originating from outside Canada points to disparities in FASD diagnosis among Black populations.

For example, the authors of an early US study discussed such disparities, identifying that Black infants had a seven-fold increased risk of a fetal alcohol syndrome (FAS) diagnosis compared to their White counterparts after controlling for maternal confounders, such as drinking patterns, age, and chronic alcohol use.[26] Additional research conducted in the US further expands on differences within FAS(D) risk when comparing average alcohol consumption across races.[27] Oh et al.[27] aimed to assess the racial and ethnic differences in the risk of giving birth to a child with FAS associated with alcohol use during pregnancy. They identified that the risk of giving birth to a child with FAS did not differ by more than 3% across Black, White, and Indigenous populations when controlling for alcohol consumption, with Black individuals having the highest risk at

13%.[27] Although there was no difference in the risk of giving birth to a child with FAS, the authors observed that average alcohol consumption varied across races.[27] Black peoples were noted to have the lowest average alcohol consumption ($M_{\textit{average alcohol content}} = 27.05$ grams/day) compared to White ($M_{\textit{average alcohol content}} = 30.13$ grams/day) and American Indian/Alaskan ($M_{\textit{average alcohol content}}=42.62$ grams/day) populations.[27] The results of these studies therefore suggest that there is no racial or genetic difference that explains the disparity observed within FASD diagnoses, given the similar risk of giving birth to a child with FAS(D) and the overall lowest average amount of alcohol consumption among Black peoples.[26,27]

Additional research conducted in South Africa, a country noted to have the highest documented prevalence of FASD,[28] also points to the increased prevalence of FASD within Black and mixed ancestry populations.[9,29] When comparing the prevalence of FASD between these two populations, researchers diagnosed 96 new cases (6.4%) among first-grade students. Although there was no significant difference noted in the prevalence of FAS and FASD between the mixed ancestry population and the predominantly Black population, the rates of diagnosis were still elevated in both, leading the researchers to highlight two essential themes.[9]

First, although FASD in general is often underdiagnosed or misdiagnosed,[30-32] FASD is particularly underdiagnosed within Black populations.[19] For example, of the 96 newly diagnosed cases of FASD in both populations, 57 cases of FASD were identified in the predominantly Black population as part of this study, even though the children had characteristic behavioural, dysmorphic, and/or neurological/neurocognitive features of FASD.[9] As a result of this previous underdiagnosis and missed diagnosis, resources, such as available financial grants, could not be disseminated to these families, showcasing the importance of accurate recognition of FASD for not only the child to receive supports but also for the family.[9]

Second, the authors[9] further offered potential explanations for the observed increased prevalence of FASD among Black communities. Proposed explanations included historical drinking behaviours that may have facilitated a culture of binge drinking and varying social determinants of health (e.g., employment, housing stability, geography).[3] Although the generalizability of this study to a Canadian context is limited by cultural and historical differences, the perspectives revealed are crucial for further consideration of the prevalence of FASD diagnoses within Canada, how this prevalence may vary across race and culture, and potential explanations for these disparities. Furthermore, although this study cannot be directly extrapolated to a Canadian context, the results of this work should also be considered in the context of adoption,[33,34] especially among intercountry and transracial adoptions,[35] as there has been an identified increased prevalence of PAE and FASD among internationally adopted children, highlighting concerns for missed or misdiagnosis.[33,34,36]

In addition to assessing the disparities in the prevalence of FASD, it is essential to acknowledge the gap in accessing and obtaining a diagnosis. The diagnosis of FASD relies on facial features typically assessed against European standards, which are potentially subject to clinician bias and misjudgment in cases involving individuals of non-European descent.[37] In a study by Coles et al.[37] comparing five systems commonly used to guide an FASD diagnosis, the authors demonstrated that Black individuals were diagnosed more frequently in three diagnostic systems, including the Emory Clinic system, the Seattle 4-Digit system, and the Hoyme modifications. This discrepancy relates to the finding that Black youth are at increased likelihood of both being mislabeled as having FASD and/or falling through the cracks in the health system and never obtaining an appropriate diagnosis.[19,37] Together, this research emphasizes the importance of considering the social and structural determinants of health (e.g., income and social status, employment, education, childhood experiences, physical environments, social support, access to health services, gender, culture, etc.), Anti-Black and medical racism, stigma, and negative perceptions of both individuals with FASD and Black peoples that may result in profiling, surveillance, and potentially biased judgements.

The impact of misdiagnosis was shown in a case report by Ergun et al.[19] in the US, about a young man named "DeShawn". DeShawn was initially diagnosed with ADHD, ODD, and disruptive mood dysregulation disorder (DMDD) without further investigation into the possibility of PAE. After DeShawn was able to access additional assessment, the possibility of PAE was identified, and his list of diagnoses was transformed to "neurodevelopmental disorder associated with prenatal alcohol exposure, ID, ADHD, and unspecified depressive disorder."[19] The lack of an early diagnosis in this case likely limited the services and supports that could have been provided to DeShawn, demonstrating the significant importance of early and accurate diagnosis of FASD. In addition, the lack of access to an appropriate diagnosis may result in adverse outcomes for racialized youth with PAE and FASD, including disrupted school experiences and increased interactions and involvement with the criminal legal system.[38-40]

The limited research surrounding the diagnosis (or possible diagnosis) of FASD within Black communities also extends to qualitative studies of lived and living experiences. For example, in two recent studies exploring the experiences of suicidality among youth with FASD, the authors highlighted intergenerational trauma, ongoing racism and discrimination, and white supremacy, and their potential impacts on health outcomes for Black, Indigenous, and mixed-ethnicity individuals.[41,42] The intersectionality of racialized groups has been identified as being prominent to their biopsychosocial wellbeing across the lifespan, particularly regarding the interplay of intersectional identities and racial trauma (e.g., an event of racism or cumulative events over time, resulting in an individual's experience of stress and consequent mental health challenges).[43,44] These complex and social-environmental factors (i.e., the social and structural determinants of health) emphasize the need for further research and discussion regarding PAE and FASD within Black communities in Canada.

Taken together, it is evident from emerging research that racial disparities exist within the diagnosis and lived and living experiences of FASD among Black communities. Researchers have identified that the social and structural determinants of health remain a significant contributor to the disparity in FASD prevalence, including among Black peoples. However, a specific etiology has not yet been identified.[26,27,41,42] In a recent article by Rockhold et al.,[45] the authors emphasized the importance of social and cultural determinants of health in understanding and addressing FASD in Black communities. For example, factors such as increased alcohol availability, lack of access to prenatal care, and lack of access to mental health resources for those with substance use challenges are all relevant to understanding the risks of FASD within

Black communities.[10,45] However, there are critical gaps in our understanding of the prevalence of FASD in Black communities, as well as how and when these diagnoses are made.

It is important to note that many of the research findings described here originate outside of Canada and, because of differences in population demographics, culture, and history, generalized conclusions cannot be fully applied to Black Canadians with FASD. Thus, there is a need for increased attention to trends at the intersection of being Black with FASD in Canada, including quantitative and qualitative evidence, to further drive policies aimed at decreasing the gap faced by Black peoples with FASD and their families.

Implications and Recommendations:

- Although this gap analysis focused on the limited available research addressing the intersectional considerations of being Black with FASD, it is imperative to note that Black peoples and communities are not one homogenous group. Research, policy, and practice considerations that advance knowledge and support for Black peoples with FASD must account for the unique intersectional experiences of diverse Black peoples, including factors such as age, sex, gender, immigration status, adoption identity, language, culture, socioeconomic status, and other social and structural determinants of health. These factors are crucial in addressing potential barriers to identification and support for PAE and FASD, developing context-specific diagnostic and care practices, and in combating systemic and structural Anti-Black racism and oppression in the context of FASD.
- Additionally, our gap analysis focused primarily on the intersection of being Black with FASD in the health care system. However, it is also essential to consider intersectionality and FASD across multiple systems, including within the criminal legal and educational systems. For example, “cultural overshadowing”, also known as racial bias, has been identified as a concern in the criminal legal system.[46] Although FASD can occur in all racial and cultural groups, indicators of FASD may be obscured by assumptions and biases about cultural and ethnic indicators.
- Our gap analysis also outlines preliminary understandings of the intersection of being Black with FASD. Although evidence in this area is new and emerging, it is clear that Black individuals with FASD and their families experience compounded issues of stigma, discrimination, and Anti-Black and structural racism, similar to other established domains of health care and social services. Further work is needed to understand how broader racialized societal stigmas (e.g., about alcohol use,[47,48] parenting,[49,50] Black communities,[51,52] etc.) intersect with existing stigmas about PAE and FASD and contribute to the preliminary trends identified in this analysis. Furthermore, additional work is needed to understand the diverse experiences of Black peoples in the context of PAE and FASD, including critically under-researched populations such as those who are internationally adopted, those who may be immigrants to Canada, those who are asylum seekers, and/or those who are refugees.
- The collection and reporting of data on race and ethnicity in health research, in a culturally informed manner that is responsive to the diversity of Black communities, is important, including in research on PAE and FASD. When equity-seeking populations are

reported together as aggregated groups (e.g., visible minorities, racialized groups), these categories may conceal underlying inequities in health experienced by diverse groups, including Black peoples.[53] It is important to acknowledge the significance of systemic and structural racism in the health care system and the implications of collecting race-based data because of historic racial trauma and ongoing discrimination, with inappropriate data usage perpetuating more harm. The collection and use of data must adhere to frameworks like the Engagement, Governance, Access, and Protection (EGAP) framework, which was developed to guide appropriate health data collection for Black communities.[54]

- Researchers and clinicians should be aware of the impacts of racism and racial discrimination and their implications for mental health among racially diverse groups. There is a need for further research, particularly in the context of PAE and FASD, to understand the intersections of racial trauma, neurodiversity, and substance use. Longitudinal research that tracks outcomes over time will be instrumental in understanding the long-term impacts of neurodevelopmental disabilities in Black and underserved populations, offering insights into how healthy outcomes can be fostered for people with FASD and their families in these communities. More research on the lived and living experiences of Black Canadians with FASD, as well as their parents, caregivers, and families, would also be especially helpful in this area, particularly research that is sensitive to unique and diverse cultural contexts.
- Increased funding is needed to capture culturally informed resources and supports for people living with FASD and pregnant people who identify as Black. Services and supports must employ an intersectional lens when providing care and supporting diverse families, including parents and caregivers raising Black children with FASD.[55]

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