

“Blackness, Blood, and Borders:” Anti-Black Racism in Disabled Children’s Health Care Spaces as Epistemic Violence

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The lives, selves, and social worlds of racialized disabled children and their parents have been hidden and silenced under the weight of grand metanarratives about the white disabled child. In this way, the centrality of the white disabled Eurocentric child is a symbolic violence that has erased the lives of other children, especially Black children and their families. In this qualitative interpretive study, we utilized a theoretically informed approach to explore the parenting journeys of Black parents who care for disabled children. We found that anti-Black racism, as symbolic violence, was constituted by health care narratives about biological determinism. Health systems also symbolically violated the lives of Black mothers through practices of bodily control and surveillance, and the wisdom and generational knowledge of Black mothers as experts on their children’s lives was erased through the practice of being rendered incompetent. Implications: Following calls by Black feminists, we suggest that scholars, theorists, and clinicians must theoretically and empirically center the lives of Black mothers with disabled children while recognizing the grave harms of anti-Black racism in children’s hospital spaces.

Key words: Black, anti-Black racism, childhood disability, health systems

In the study we describe below, which chronicles how Black mothers navigate Canadian health care systems with children who have disabilities, a Black mother in Canada reflects on her interaction with a white pediatrician during her child’s diagnosis. This mother comments on a racist health care experience she encountered with a white health care provider. This mother says, “*I will never forget what you did to me and my son.*” In so doing, this mother illustrates the profound and unforgettable nature of anti-Black racism in pediatric health spaces.

This study details nuances of anti-Black racism (ABR) from the perspective of Black mothers who provide care to children with disabilities as they navigate the Canadian health care system. We illustrate how health care encounters are often shaped by unspoken biases and power dynamics, especially when these intersect with race and disability. Our findings challenge contemporary understandings of everyday childhoods by illustrating the additional adversities and struggles faced by Black mothers and their children with disabilities as they navigate the turmoil of ABR in modern-day health care spaces. Our findings also illustrate the importance of turning to Black mothers, not only as experts on their children with disabilities, but as sage knowledge keepers and holders about the damaging impacts of ABR on children and childhoods.

The *Journal of Childhood Studies* poses critical questions about children and childhoods. One of these challenges is to seriously engage with the social worlds of children, including their ontological and epistemic inheritances. The journal also calls on scholars to engage with the Eurocentric practices that shape children's everyday lives. The health care system is one space and place that bears down heavily in children's lives, and, in the case of this study, in the lives of Black children with disabilities specifically. As witnesses and guardians of their children, the Black mothers in this study offer us a rare opportunity to take stock of the colonial and Euro-Western health care navigation experiences they negotiate with their children. Our article responds to these critical questions by illuminating some of the injustices of colonial Eurocentric health practices in the lives of racialized children with disabilities and the parents who care for them.

In the past four years, there has been more media and public attention on the dangers of ABR on Black people, groups, and communities (Lopez & Jean-Marie, 2021). This has been a largely public dialogue that has unfolded in news media. However, the nuances and particularities of ABR in the lives of children with disabilities and their parents is a notable silence, both in contemporary dialogues about ABR and in theoretical and empirical evidence on children and childhoods. The experiences of Black mothers, specifically, in navigating health care systems with children with disabilities is also a notable data silence.

In this article, we reflect on a qualitative study on race and childhood disability that we have undertaken over the past five years on the intersection between childhood disability and race in the HEART lab in Toronto, Canada, led by Professor Fiona Moola. (HEART is an acronym for health experiences and arts-based research team.) Using narrative and art-based data from the study and focusing on the narratives of three Black mothers who identify as the parents of children with disabilities, we illuminate the unique particularities and intricacies of ABR in the lives of these mothers as they navigate health systems with their disabled children. It is urgent that the continued exclusion and omission of ABR stories in the childhoods of children with disabilities be addressed to stop this epistemic violence. We are also aware that while Black and racialized people share common experiences, ABR is a particularly severe, unique, deadly, and virulent racism that is particular to Black communities. We resist conflating oppressions and recognize the urgent need to give space, time, and scholarship to experiences of ABR.

Self-reflexivity is generally considered to be a marker of high-quality qualitative scholarship (Karcher et al., 2024; Watt, 2007). Reflective research practices are necessary to understand how the self is embedded in research. Reflexivity is also necessary for managing emotionally heavy qualitative research, such as stories of racism and ableism. Thus, we offer the following. We are a team of scholars—professors and graduate students—at Toronto Metropolitan University and the University of Toronto. We are all racialized people who have experienced the harms of racial violence in some way or another. Racial trauma in itself can be considered epistemic violence because it discredits and disavows some aspect of the self (Karcher et al., 2024). Fiona is a brown woman with ancestral roots in apartheid South Africa. She is a new mother to toddler twin girls born prematurely. One twin lives with a treatable long-term orthopedic condition known as developmental hip dysplasia, and the other lives with pediatric asthma. Kathia is a Black Canadian woman and Nivatha is a Tamil Canadian. The non-Black writers on our team recognize that while there are similarities in experiences of racism between Black and brown people, we cannot know or understand the pain and turmoil of ABR since we have not experienced it directly. Additionally, although our article does not engage the voices of Black children with disabilities directly, and this is a limitation of our work, we suggest that many insights can be gleaned from our work with Black mothers. A canon of work already exists in Black feminist and Black mothering literature (e.g., Brantley, 2023; Guillory, 2022; Love, 2016). It is important to not essentialize motherhood or mothering. As well, mothers' voices cannot be seen as a proxy for their children's. With those cautions in mind, mothers' insights are of tremendous value because they offer caregiving narratives and provide insights into health care navigation struggles around raising children with

disabilities.

Review of the literature

Before exploring the health care system navigation experiences of Black mothers, it is necessary to unpack relevant literatures. Briefly, Black bodies are ascribed social and moral value through the process of racialization. Racialization, as a process, acquires social and economic significance. When socially constructed categories (such as race and disability) are associated with race and then reinforced in institutional responses, hierarchies are created and entrenched in policies over time (Mele & Adelman, 2015). Indeed, the unique intersection of race, disability, and ABR—especially as it unfolds in the context of hospital spaces—is an unspoken and unaddressed narrative. The prevailing view often treats racism and ableism as distinct, parallel mechanisms of oppression that independently reinforce societal hierarchies (Simmons & Slayter, 2023). This perspective not only overlooks the lived experiences of individuals of colour with disabilities, but it also neglects to scrutinize the ways in which race is pathologized to uphold racism (Chisholm, 2020; Simmons & Slayter, 2023).

It is important to note that there is a small and burgeoning body of evidence on the harms of racism and ABR in particular. Several authors have documented the existence of racism within the professional practice and discipline of pediatrics and pediatric medicine. Pediatrics has been complicit in the development and perpetuation of racism (Raphael et al., 2024). For diseases and disabilities that have demonstrated a race-based pattern that disproportionately impacts racialized children, such as childhood asthma, few scholars and clinicians have identified systemic racism as part of the root cause of disease disparities (Lovinsky-Desir et al., 2024). ABR is a particular form of racism directed specifically at Black bodies. It is a more virulent racism, given the propensity for violence. It is also virulent given the embeddedness of ABR in systems such as policing. Some scholars have noted the presence of ABR, specifically, in the discipline of pediatrics. Here, for instance, Black children are known to experience pervasive and systemic health care problems in comparison to white children, such as high asthma prevalence, poor access to organ transplants, poor pain management, and poor surgical outcomes (Jindal et al., 2020). Qualitative studies on ABR in pediatrics are few and far between. However, Kaler-Jones (2022) chronicled experiences of ABR in outpatient health settings experienced by Black families, and also documented families' suggestions on how to establish anti-racist health care spaces.

Scholars have generally not considered ABR to be a form of epistemic violence and injustice. Despite this omission, given this study's ABR epistemic violence focus, it is important to critically unpack this literature. Epistemic violence was a term first proposed by Gayatri Chakravorty Spivak (1988) in her original text "Can the subaltern speak?" Spivak employed this term in the context of postcolonial studies and the growing critique of the colonial world (Dotson, 2011). Broadly, epistemic violence refers to the complex ways in which the colonial project engages in the chronic practice of silencing the Other (Dotson, 2011). This complex silencing entails suppressing both the knowledge and the practices of the Other; it is relevant to the current study given the chronic suppression of Black mother's voices. For Spivak, epistemic violence is particularly damaging because it can lead to the complete and total eradication of the knowledge and ways of knowing of the Other (Dotson, 2011). Fricker (2007) extended the concept of epistemic violence to propose the notion of epistemic injustice, which, like epistemic violence, occurs when a particular body is not regarded as a knowledge holder (Fricker, 2007).

The suppression of parent and caregiver voices

In this article, we use the term caregiver in addition to parents because it is a more inclusive term when referring to the homelife of children whose family relationships are unknown to the researcher (Coalition for Diversity and Inclusion in Scholarly Communication, 2022). Although literature on caregivers and epistemic violence is scant,

this literature is nevertheless extremely important. Literature on epistemic violence and caregivers has explored a variety of different caregiver roles. The suppression of voice as a form of epistemic violence is important here, given the chronic silencing that the Black mothers in this study experienced as they navigated health spaces with their children who had disabilities. As we did in our study, one group of scholars found that young Black mothers of newborn babies were subjected to epistemic violence by obstetricians during labour and delivery (Chadwick, 2019). Specifically, these young Black mothers' knowledge of their bodies and their babies was silenced and muted during the labour and delivery process. These practices serve to colonize the labour and birthing narratives of young Black mothers. Another team of scholars investigated practices of silencing through epistemic violence that are faced by female caregivers of abusive older people who have high care needs. Specifically, these female caregivers engaged in practices of self-silencing and were keenly attentive to moral anticipatory losses (Bailey & Mobley, 2019; Baumtrog et al, 2019; Burroughs & Tollefsen, 2016; Chadwick, 2019). Additionally, there were limited linguistic resources available to these women, and they often lacked a discourse to hold these abusive family members accountable for their actions, given familial connections to the women. The disproportionate removal of Indigenous children from their families by (settler colonial) social services agencies can also be viewed as a practice rooted in epistemic violence (Wright et al., 2025).

Scholars have contributed toward our understanding of the harms of racism and ABR in particular, as well as our understanding of epistemic violence and epistemic injustice and why the chronic suppression of voice may be dangerous. However, scholars have not considered ABR to be a form of epistemic violence and epistemic injustice, nor explored the epistemic violence/injustice experiences of Black mothers parenting disabled children in health spaces. Such investigations are important because, if we draw on the archives of social justice movements, such as the Black Panther Party and the National Black Women's Health Project (BWHP), we begin to identify common qualities of Black disability politics and the need to ground public health initiatives in the experience and expertise of marginalized groups as a form of liberation (Schalk, 2022). The BWHP's work highlights the importance of considering how policies and health care practices disproportionately impact Black women, especially in the context of disability (Schalk, 2022). Advocating for culturally competent care, mental health resources, and systemic changes within health care institutions is critical. The BWHP also stressed the need for community-based solutions, where Black women's voices and experiences shape the development of programs that support both their health and the health of their children. These experiences serve as a vital framework for addressing the intersectional realities of Black motherhood, disability, and racism in health care. Centering these issues fosters a more inclusive understanding of how disability politics must confront the unique challenges faced by Black women, ultimately working toward a more just and equitable health care system.

In the sections that follow, we explore the health care experiences of Black mothers providing care to children with disabilities in Canada. We trace their experiences through health care, chronicling the nuances of the ABR they have faced with their children in these spaces. In our discussion, we offer a rationale for why these moments constitute epistemic injustice.

Methodology and methods

To explore the health care system navigation experiences of Black mothers, methodologically, we utilized a decolonizing case study methodology informed by arts-based research principles. We adopted this methodological approach given that decolonizing perspectives purposefully aim to disrupt Eurocentricity and whiteness in research. We felt that this perspective would enable us to better understand participants' experiences of marginalization in a way that attends to societal oppression and avoids blaming the victim. The case study methodology provided us with the opportunity to explore the intricacies and nuances of three Black women's lives that might be lost with

research approaches that employ a larger number of participants. These two methodological frameworks intersect because they both value and recognize the importance of attending to the narratives of individual lives in a way that considers power imbalances and experiences of oppression.

Decolonizing case study methodologies

In this article, we focus on participants' verbal narratives regarding epistemic violences. Through this particular methodological offering—decolonizing case-based research—it is possible to attend to the nuances and particularities of three individual stories while, at the same time, actively engaging in deconstructing and decentering whiteness and Eurocentricity in research (Kessi et al., 2020; Smith, 2021). In this empirical study, we embrace methodological pluralism as well as bricolage. Here, methodological pluralism refers to the ability to be flexible in one's research approach. Methodological pluralism encourages researchers to embrace different methodological approaches for different intellectual pursuits and intentionally avoids methodological fundamentalism and purism (May et al., 2017). We utilized a pluralistic approach by blending methodological approaches instead of fixating on only one. This allowed us to draw from the benefits of both decolonizing and case study approaches (Payne, 2006) in our investigation of Black women's health care system navigation experiences.

Decolonizing methodologies (DM) were first proposed by Indigenous scholar Linda Tuhiwai Smith (1999/2021) from New Zealand. DM have been widely taken up and adapted across a range of disciplines. Fundamentally, DM take stock of the ongoing impacts of settler colonization, including the ways in which settler colonial ways of being have infiltrated the organizations and institutions of daily life. DM also recognize that colonialism has served to repress and also suppress other epistemologies. The suppression of knowledge systems outside of the West by colonization, then, is something that decolonizing methodologies have in common with epistemic injustice scholars. DM emphasize the importance of listening to marginalized communities to amplify and elevate their voices (Smith, 1999/2021). They emphasize naming historical violences—like the development of Canada's food guide, which was created based on experiments with nonconsenting starving Indigenous children (Johnson, 2021)—that have occurred in the name of research. Finally, DM scholars emphasize that decolonization is never an arrival point or a linear path; rather, it is a lifelong circuitous process and journey.

The case study methodology we employed was inspired by Stake (1995). Case study scholars emphasize the tremendous value and importance of listening and attending to the unique particularities of an individual's life. Although case study methodologies are often criticized for not being “generalizable,” generalizability is an epistemic tenet from quantitative research. Case study scholars emphasize the importance of not subjecting case methodology to the rules that reside within other epistemologies. The case study, which has been employed for decades, provides scholars with a unique opportunity to attend to the details and contextual elements of one person's life (Stake, 1995).

Conceptual framework

We have also drawn on a few theoretical strands from Black feminisms and Black feminist disability studies. Black scholars such as Hickman (1997) note a centuries-long legacy of Black exclusion, not only from social, political, and legal life but also from knowledge production. Black communities have also been the target of epistemic violences such as the practice of the “one drop rule” (Lavender, 2020). Dating back to the 17th and 18th centuries in Virginia and Maryland during racial segregation of the American South, notions of purity and contamination were used to curb the threat of miscegenation (Hickman, 1997). Whiteness was believed to be unblemished and pure. Thus, a single drop of Black blood rendered one Black, thereby excluding everyone with Black ancestry from white society (Khanna, 2010). In the late 1800s, Booker T. Washington, a prominent educator, suggested that even

one drop of African blood flowing through the veins rendered one non-white (Khanna, 2010). This law certified that Blackness, denigrated under enslavement and Jim Crow segregation, required social and legal principles to maintain hierarchy and afford distinct privilege to white people (Lavender, 2020). Codified laws and regulations gave rise to institutionalized discrimination that permeated society. This has included access to education, housing, employment, and health care, and these barriers remain today. Discriminatory practices such as the one drop rule led to internalized racism rooted in racial identity, ableism, and legacies of inferiority. Such legacies were used to justify epistemic injustice. Racial categorizations such as the one drop rule have solidified binary perceptions of race, creating lasting legacies of ABR, violence, and erasure of the acute experiences of cultural bias and normative assumptions. Oversimplification of intersectional experiences results in insensitive and inappropriate interactions, particularly within children's health care spaces.

Some Black feminist scholars have called for the integration of Black studies and disability studies to enable an ethos of care in the context of disability (Bailey & Mobley, 2019). These scholars note the omission of Blackness from traditional disability studies approaches and call on frameworks such as Black feminist disability studies to offer an intersectional engagement of Blackness and disability (Bailey & Mobley, 2019). These scholars have also noted the social construction of the "hyper strong" Black female body and the expectation that Black bodies should be able to endure and transcend all forms of suffering. It is thought that these problematic tropes largely arise from the enduring legacy of slavery. As part of the hyper strong Black body discourse, Black bodies are often expected to be "twice as good" as non-Black peers, which these scholars note may also be a form of insidious ableism (Bailey & Mobley, 2019).

Participants

For the case study presented in this article, we are drawing on the narratives of three Black mothers who parent children with one or more disabilities. The participants were recruited using the research-ethics-board-approved recruitment method, including posted study advertisements and word-of-mouth sampling. Specifically, two Black mothers responded to study advertisements that were shared via social media platforms such as Facebook, X, and Instagram, and one Black mother was introduced to the study via word of mouth from a past participant. After hearing about the study, they all reached out to the research coordinator and completed the consent process to ensure they fit the study's inclusion criteria: (a) identify as the parent of a child with disability in Canada, and (b) identify as a racialized person. Each mother self-identified as a person heavily motivated by racial and disability justice, and these motivations spurred their engagement in the study. They aimed to present their narratives in a scholarly context to ensure that their stories contributed to academic, scientific, and general knowledge. Although there were no major ethical issues that emerged during the study, as researchers, we experienced the narration of ABR narratives as emotionally charged and upsetting content. Further, as researchers, we also noticed that the participants all experienced considerable life stress and adversity, such as precarious work, poor health, and relationship challenges.

All three participants identify as Black women. They live in Canada and identify as the primary parent of one or more children with disabilities. Joy is the mother of two Black autistic sons. Marta and Lily are also mothers of children with autism.

Methods and analysis

In-depth semi-structured interviews were used with all the participants to gather data. This provided us with the opportunity to inquire after important concepts, such as experiences of race and racism while navigating health systems. However, the semi-structured nature of the interview also allowed us to follow and pursue novel

insights raised by the participants, such as their health care experiences when giving birth or attending doctor's appointments, interactions with educators about their child's academic success or behaviours, and the social stigma and discrimination they faced while raising a child with a disability. Research assistants interviewed each participant for approximately 90 minutes on Zoom or in person. The sessions were audio-taped and transcribed verbatim. Working on the transcribed data, we searched for underlying themes by developing layers of coding, from open codes to categories to final themes. This sequential data coding process allowed us to generate larger themes of experience that were common to all of the Black mothers (Joffe, 2011). Participants made artistic portraits about their experiences as racialized parents over the course of several months.

Findings

Our case study findings are reported below. These themes were developed through our thematic data analysis process described above that entailed a rigorous three-step coding process. Due to limited space and time in this paper, we only address three epistemic injustices that these three Black women experienced as they navigated health care systems and spaces or sought out health care for their children with disabilities. All of these spaces, in some way, related to caregiving actions that the three women were trying to take to better safeguard their children's health. The epistemic injustices were (a) biological determinism, (b) surveillance and control, and (c) being rendered incompetent.

Biological determinism

The participants shared painful stories of how their Blackness was constructed and referred to in health care spaces by white health care providers. One mother, Marta, had to spend several weeks at a large children's hospital when her child was admitted as an in-patient to the hospital unit. When Marta was at the hospital with her son, she endured both covert and overt racism and microaggressions from white health care providers. In one of these cases of overt racism, a health care provider working on her child's inpatient unit referred numerous times to her child's skin colour, describing him as a "very dark-skinned baby." When the mother appeared incredulous, the health care provider invoked a discourse of biological determinism. She explained that because the mother had "Black blood" in her, this was the reason why her child was particularly dark. Thus, the nurse used racist scientific logic to explain why the child was particularly dark in skin tone. At this point, Marta could not believe what was happening but figured right away that she had to be extra vigilant with the health care providers working with her and her child because more racist comments might potentially be spewed her way, disguised as logical, scientific explanations. Here, oversimplification and cultural incompetence were thought to be acceptable due to institutional racism.

When my daughter was born, she was born and was very purple, really, really dark when she was born. I was really struck by that. I kept asking staff if that was normal, if there was not an issue about that, and I was very preoccupied with that. ... At one point there was a pediatric student. I asked her the question, like are babies born that dark, that purple, could that be a sign of any health issues? And she told me, and she didn't know me, she didn't ask me any questions. She said that because I had some Black blood in me, sometimes children are born with a blue tinge, and I couldn't believe it. I said is this real? Is she really telling me that? ... Right from the start I thought, holy moly, what's going on in her mind? So that was the first warning for me, that I have to be on my toes and be careful.

The same mother was walking in the pediatric ward a few days before her child's discharge from the hospital. It can often be quite warm in temperature on pediatric units. Another health care provider, this time a physician, stopped the mother to warn her about the cold Canadian temperature outside. She also instructed the mother on

the importance of keeping sick babies warm, especially if they have underlying health conditions. Here, the health care provider assumed a “psychological ineptness” and maternal incompetence on Marta’s end. This is part of the cruel, racist construction of the Black body outlined by Black feminist disability studies scholars discussed above (Bailey & Mobley, 2019). The mother felt that the physician waited for her husband to leave before beginning her instructional talk about Canadian climate systems. The result was that Marta was alone and isolated when the health care provider lectured her about the weather.

When my daughter had her first surgery at [a Canadian] hospital, at the time my hair was all matted because my mother would come and stay with us and she would do my hair. So I think it was more obvious that I was Black or had some Black origin in me. So I was at the hospital and my daughter had her surgery. She was doing better and we were going home. My husband went home to get some stuff or get the car, and I was alone with the pediatrician on the ward. I was dressed, I don’t know, it was very hot in the hospital, so I had a t-shirt and maybe, I don’t remember, but she looked at me and said “Do you know it’s winter outside and it’s really cold, and you need to dress up. You have a daughter who’s going to have a lot of health appointments and you’re going to have to be really serious and focused about it.” And I thought holy moly what does she think? I thought, does she say that to every parent? And I just thought that she’d waited for a moment when I was going to be alone, when my husband was not there to tell me that, as if she needed to “put some sense” into me.

Lily also commented on the way that health care providers racialize her Blackness in hospital spaces. Lily has dreadlocks and so does her husband. Upon seeing the couple at the hospital with their child, health care providers sometimes resort to pejorative and stereotypical assumptions and comments. These grossly inappropriate comments serve to render and conjure Blackness and deflect focus away from caring and attending to their sick child. These comments are also laced with discourses of exoticism and biological determinism. Health care practitioners failed to provide an appropriate, culturally safe interaction for Lily, her husband, and her child.

They (doctors and staff) often talk to us like, ‘cause we both have (dread) locks like, “Hey, man, I remon!” Like, are you fucking kidding me? Like this is our? We walk into the office and they are like “Hey man, wah gwan, hey remon, hey!” Like they (health care staff) start talking like Bob Marley, you know, making reference to Ganja like. Are you dumb? I’m here with my 3-year-old child, or like, who’s talking like that? This is the type of stuff I’ve had to—I’m often the advocate. And maybe you’ve done this for 10 other black families. No.

Thus, white health care providers in health care spaces often adopted discourses of biological determinism that render and conjure the Black body. Their comments were interpreted as racialized, extremely derogatory, irrelevant to their child’s care needs, and laced with stereotypes and assumptions. The racist and stereotypical actions taken by the white health care providers disregarded the medical and health needs of the ill child, resulting in increased levels of stress, anger, and anxiety for the mothers responsible for the child’s care.

Surveillance and control

The participants also alluded to external surveillance and control that served to police, monitor, and govern their Black bodies. One participant had to cross the Canada-US border with her husband to get access to surgery for her disabled child. We have included this geographical border crossing because it was related to a Black mother’s health care pursuits. Border control stopped the family, separated the family members, and proceeded to search for drugs and other illicit substances. The border control officer adopted discourses of risk and danger to excessively police this Black family who was merely trying to access health care for their disabled child. Sadly, to enable the police search of the Black family for drugs, the Black couple was pulled off a medical bus and separated from their disabled child. For this mother, searching and separating due to Blackness is a normative part of her life.

My son had to go to X (name of American city removed for anonymity). All his surgeries are at X (hospital name removed). We used to go across the border. They checked our (dread) locks for drugs and pulled us off of—and I mean there's four families, we're the only Black family—me, his father, and him are both pulled off of a surgery bus, which is obviously a medical bus. And we're the only family that was pulled off. This is just what happens. This is just my regular life when we travel—we're always pulled in the back room where they need to swab and check his prosthetic in case it's we're hiding hash or cocaine in there. They're always doing this kind of craziness. And this is just us going for a surgery which is already so stressful. And then I'm always dealing with this stuff on top of it. You know. It's pretty wild. But they constantly like checking our (dread) locks for stuff where I'm like "What? What could I ... ? I don't know what you think I'm going to ... like, I don't know what kind of time you think I have, but it's quite madness.

These racist actions, for this mother, feel like a heavy emotional burden to carry.

Those type of things I'm just used to, but they just add that extra like log or whatever put on my shoulders. It's already heavy what we're doing, and then I'm always given more weight to carry. And that's just my life with the medical field, constantly.

This mother also felt that her child's access to pain medication, which is crucial in the postoperative period, was curtailed because of his Blackness and the pejorative assumption that because his Black parents must be addicts, he deserves less access to pain relief. The mother observed that non-Black children received more medication than her son did after surgery. Medication denial left her son vulnerable to pain after surgery. It also invoked the racist stereotype of the "invincibility of the Black body" (Bailey & Mobley, 2019), thereby promoting the notion that the Black body somehow does not require medication. This reflects some of the racist stereotypes discussed above.

Or my son, them not giving him Tylenol, not giving him enough morphine like. Do you think we're drug addicts? You think I'm trying to sell his morphine on the streets, or like it's crazy when I see a different parent and I ask lots of questions, especially after surgery. Maybe she's given like four bottles of morphine to take home, you know, and maybe 80 milliliters or something. We will be given two bottles of morphine. And we should, I should, wean my son off of morphine. Limb-lengthening surgery is cutting the femur in half, inserting nine pins into the bone. And they want to give him morphine for two weeks, like are you crazy, the throbbing. And so sometimes I'm like, hmm!

When mothers were trying to gain health care access for their children, their Black bodies were surveilled and controlled by white authoritarian people.

Rendered incompetent

Black mothers of children with disabilities were often rendered incompetent in health care spaces as they navigated health systems. Their knowledge, wisdom, and insight as parents of children with disabilities was frequently questioned or minimized. This invokes the racist stereotype of "psychological ineptness" that is outlined by Moya (2019) in which Black bodies are seen to be mentally inept. For example, many of the white health care providers that Joy interacted with during her child's long autism diagnostic process constantly questioned her knowledge and decision making. They often labelled her as an anxious helicopter mother instead of honouring and acknowledging her wisdom and insights as a parent. Joy also felt like the constant dismissal by white health care staff delayed her child's diagnosis of autism. Joy suggested that being single, living in a shelter, and having a very youthful appearance contributed to the dismissive gestures she received from white health care staff.

Mm. Um, so I just told my doctor that I believe that it is autism because we've been dealing with this now for like 15 months. And I've been seeing him and because I'm a single parent, because I'm a

younger, younger mom, I was young, but a younger mom. And, um, you know, because I'm a Black woman, um, I think it, I was just dismissed, and he is, he called me a helicopter parent and stuff. So I think, um, the pro, like my son could have been diagnosed, you know, earlier, but, you know, he wanted to wait. I asked for a second opinion and I was also fluffed off there too.

Joy reflects on the arrogant ethos of expertise that the doctor projected rather than honouring her wisdom and knowledge as a mother.

She was like "I'm the doctor, you know, I know everything about autism." Like just her, her demeanor and stuff towards me, especially like, you know, I was coming the summertime. I had my tattoos, my piercings, and. And I just felt like, "Hi, oh, sorry. Hi, you need something?" "Uh, excuse me Oh yeah. She was very domineering and just, you know, "I'm the doctor!" And it was like, I didn't know anything about autism. Like I'm not a specialist, but this is my child I see every day. And she would question me like, "Are you sure you saw, uh, this is him, you know, scratching at his tag or are you sure his socks really bother him?" Or what? It was just like, "What are you talking like, this is my child!" I know that he's not eating properly. Like, have you tried these foods? Have you like, have you tried to purée, have you tried to soften it? Have you tried? And it's like, I've tried everything, doc!! Actually, it was funny. I ended up seeing her again, 'cause she was at the clinic with my pediatrician and she came out of her way and she's like, "Oh hi!" And I just, I was not even feeling it. I still said, "Hey," 'cause I'm a polite person. But I said, "I will never forget what you did to me and my son—so have a great day."

Joy's frustration and anger with the dismissive actions of white doctors accumulated over time. One day, she resisted the doctor by calling out his (white) privilege. She stated:

I have to cuss him out literally in his office because of the fact that, um, he, you know, you're hands. I told him you are fed a silver spoon. You didn't have to struggle like your Black clients here. We don't connect with you. I'm like every time I come in here and try to talk to you, I'm getting blown off, but you're speaking to your people in your language. Mm. Like, we all deserve your time. You know what I mean? Mm-hmm and we all deserve your appreciation and everything. Don't just come and thank your people. Thank all of us, 'cause we're helping for you to get paid and drive that BMW downstairs.

Our findings are discussed briefly in the context of the literature below.

Discussion

In this study, we explored the health care system navigations of Black mothers who are primary caregivers for their children with disabilities. Reflecting on their experiences in health care spaces, Black mothers explained how their Black bodies were often constructed in pejorative and deeply stereotypical ways. Bodily features such as skin colour or dreadlocks were conjured in ways that adopted the logic of racist science and biological determinism. Here, genetics and other scientific discourses were called on to naturalize and explain away how and why Black bodies are different, including skin colour, the inability to sense that it is cold outside during the Canadian winter, or the texture of one's hair (Shen & Feldman, 2022; Williams, 2020). Scientific racism and biological determinism are dangerous vices. Rather than understanding race as a social construct that was invented by white people to seize power from people of colour, it naturalizes the Black body and promotes the notion that these are "natural" inferiorities. Scientific racism has a long history in medicine across several centuries. Here, bodily features like skull size, skin colour, and hair texture are conjured to depict the Black body as inferior. As per the one drop rule discussed above, this type of racist treatment speaks to the lingering impact of genetics and biological determinants as an enduring fixation on negative connotation associated with Blackness through lexicon, as well as perceived identity. As well, such biological determinism, oversimplification, and cultural incompetence are only deemed

acceptable due to institutional racism.

We suggest that the use of scientific racism (Opara et al., 2022) about dreadlocks, skin colour, and temperature sensing are forms of epistemic violence and injury for Black mothers in health care spaces. As one mother said, “We are here for our child.” These racist discourses minimize the care needs of parents and deflect care attention away from their children with disabilities. These comments also constitute both overt and covert racisms that are deeply damaging to the health and well-being of Black parents. We suggest that the presence of scientific racism in pediatric health care spaces is an epistemic violence because it ignores the perpetuation of racism by white health care providers and the impact of this on Black mothers trying to focus on the care needs of their children with disabilities. Pediatric pain is an extremely complex problem (Mathews, 2011). Pain management has remained stubbornly adultist in that we have used adult models of pain and projected them on children. One Black mother felt that her child was denied pain medication after surgery due to the assumption that she and her husband are drug addicts. These racialized stereotypes are deeply problematic as they serve to constitute Black bodies as at risk. Denial of pain medication to a Black disabled child is also an epistemic violence as it ignores the pain experiences of a Black disabled child, even going so far as to impact quality of life. Research has shown that Black patients, including children, are less likely to receive appropriate pain management compared to white counterparts due to a belief about racial differences in pain tolerance (Groenewald et al., 2018). The relationship between racial perceptions and bias in pain management decisions by medical practitioners has shown to be prevalent across medical fields, reaffirming the importance of mitigating racial biases in perception to ensure fair and equitable treatment for all individuals.

Black mothers described horrific experiences of police surveillance at the Canada-US border. Sadly, these experiences of police surveillance were a normal part of life for this Black mother. Intimate body parts, such as dreadlocks and prosthetic limbs, were searched for drugs by a heavy police presence. As well, parents were pulled off a medical bus in a deeply degrading display of ABR. Of course, brutality toward Black people by police is an enduring part of society, with some scholars suggesting that racism is built into the police force (Carvalho, Mizael, & Sampaio, 2021). We suggest that excessive policing of Black mothers when caring for children with disabilities is an epistemic violence. Like the use of biological determinism or racist stereotypes, it perpetuates the maintenance of racism in the pediatric health care system.

Although the wisdom and knowledge of Black mothers is highly valued in Black feminist thought (Collins, 2022), the capability of Black mothers to act as sage knowledge holders about their children was frequently ignored and suppressed by white health care providers as these mothers navigated health systems. Instead, the Black mothers were constructed as “excessive” and anxious.” Doctors adopted a discourse of expertise and knowledge and the tone of a “lecturer” or “judge,” which served to minimize and exclude the knowledge of Black mothers about their children. Scholars have suggested that people of colour, especially women, are often constructed as incompetent and lacking knowledge (Neimann et al., 2020). The suppression of Black mothers’ knowledge about their children with disabilities constitutes epistemic violence. If we do not hear the parenting wisdom of Black mothers on childhood disability, like Fricker (2007) has suggested, this knowledge could be erased.

Recommendations

To enable resistance, accountability, reflection, imagination, speculation, and accountability, we have several actionable recommendations for several audiences. Health care systems—and pediatric systems in particular—that work directly with children with disabilities must take responsibility for perpetuating ABR and upholding white supremacy. Public apologies can be an effective tool to employ with communities that have experienced betrayal

and broken trust (Folmer et al., 2021). Again, in the spirit of accountability, we call on health care providers and health systems everywhere to immediately terminate any use of colourism, biological determinism, and racist stereotypes and assumptions about Black mothers in the various spaces they converge with their children with disabilities. This could be achieved through educational training, workshops, and seminars for health care staff in health care spaces about how and why microaggressions and racist assumptions may be traumatizing for racialized people. We urge the careful use of reflexive language with Black mothers, and ongoing health care provider and educator training on the dangers of white privilege and its impact on Black communities. Developing reflexive language means examining our everyday speech and language practices used with patients with the view to identifying assumptions and projections about others. It also means attending to obvious and subtler racisms and microaggressions such as assuming that a racialized person does not know how to dress for cold weather. We encourage Black families to continue resisting the presence of ABR in health spaces and health providers to reimagine new ways of engaging with Black families that honour the wisdom of Black elders and families. At all times, we urge the use of radical listening and humility to learn from and with Black communities in hospital spaces.

Conclusion

Although there is a growing body of evidence on the harms of racism and ABR, there is a dearth of literature on lived experiences of ABR, most especially from the perspective of Black mothers navigating health spaces with children who have disabilities. And although there is a wealth of scholarship on epistemic injustice and epistemic violence, few scholars have theorized anti-Black racism in health care spaces as a form of epistemic violence and injustice. We suggest that ABR is integral to epistemic violence and injustice because it diminishes, disowns, and negates the wisdom and knowledge of Black mothers as they navigate health spaces with their children. In this way, it is a form of symbolic erasure and muting that continues to silence and marginalize Black mothers.

As a team of racialized scholars from Toronto, Canada, we investigated how Black mothers parenting disabled children navigate health spaces in Canada. We utilized a decolonizing case study methodology informed by elements of arts-based research. Black mothers reported three epistemic violences: biological determinism, surveillance and control, and being rendered incompetent. Using our findings, we propose a range of recommendations for parents, childhood scholars, clinicians, educators, and students, including engaging in self-reflective practices about racialized language and microaggressions. Our study is not without limitations. For instance, our work did not include Black children with disabilities specifically, and, of course, we cannot assume that mothers can speak for their children. In telling these heartbreaking tales of blood, borders, and Blackness, we hope we have illuminated the nuances of ABR in the lives of Black Canadian mothers who provide care to children with disabilities as they navigate the complexity of Canadian health care systems. Our findings expand contemporary understandings of children and childhood by unpacking the additive struggles and barriers faced by Black mothers who navigate ABR with their disabled children in modern health care spaces. Our findings also underscore the sage wisdom of Black mothers as knowledge keepers. We have also humbly attempted to grapple with a few of this journal's probing and reflective questions by illuminating and resisting the settler colonial practices that colour the worlds of Black mothers caring for children with disabilities in health care spaces grounded in whiteness and Eurocentricity. Without such reflexive practices, the knowledge and wisdom of Black mothers as the knowledge keepers about their children with disabilities will continue to be suppressed. As one mother in our study said, these moments of epistemic violence are always unforgettable.

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