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Exploring the Lived Experiences of Racialized Parents Accessing Pediatric Rehabilitation Services in Ontario, Canada: Descriptive Case Studies

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Abstract

Purpose Within the pediatric rehabilitation context, there is the lack of data in the peer reviewed literature on the intersection of race and disability. The purpose of this research was to explore the intersection of race and disability and the role it plays when parents are accessing and receiving pediatric rehabilitation services for their children with disabilities in Ontario, Canada.

Methods A multiple descriptive qualitative case study design was used. Three semi-structured interview guides were developed, and three interviews were conducted for each case, resulting in a total of nine interviews. An inductive approach was used to generate themes and data were analyzed using both within-case and cross case analyses. Intersectional and DisCrit theories informed data collection, analysis, and interpretation.

Results A total of three cases were studied. Case analysis results identified four themes for barriers to accessing services for racialized parents of children with disabilities. Parents described experiencing ableism from their cultural communities and challenges receiving a formal diagnosis. Findings also highlighted the need for diverse service providers and a desire for cultural support groups to increase comfort and belonging. At the intersection of race and disability racialized parents who have children with disabilities may be experiencing a "double burden" effect navigating compounding effects of oppression in multiple areas of their lives.

Conclusions The experiences of racialized parents of children with disabilities are complex, their broader life experiences affect the way they approach pediatric rehabilitation, and they may be experiencing a "double burden" effect.

Keywords Intersectionality · Qualitative · Disability · Race · Pediatric rehabilitation

Introduction

According to the World Health Organization [1], approximately 1.3 billion people or 16% of the global population experience a significant disability. In Canada, approximately 22% of the population aged 15 years and over have one or more disabilities, with that number expected to grow [2]. Racialized populations in Canada are also growing. Between 2001 and 2021, racialized populations have increased from 3.85 million people to 8.87 million people [3]. Specifically, about 34% of children in Canada identify as being part of a racialized group [3]. As both populations continue to grow, it presents the need to apply evidence-informed strategies to garner positive health experiences for vulnerable and racialized groups in Canada, considering the intersectionality of race and disability in a pediatric rehabilitation context.

For racialized families who have children with disabilities, they may experience barriers or inequities when accessing pediatric rehabilitation services and resources for their children leading to differential outcomes in their child's development [4, 5]. This can include communication and language barriers, creating challenges understanding, explaining, and accepting their child's disability [5] or stigma from their cultural communities leading to isolation and reluctance to acknowledge early developmental

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delays [4]. Racism and perceived racism are common experiences among racialized families who have children with disabilities leading to delayed or incorrect diagnoses [6]. In the Canadian labour market, racial and ethnic populations earn lower wages than White Canadians [7]. Families who have children with disabilities, many incur out of pocket expenses directly related to the child's disability related needs (e.g. specialized equipment, respite care) creating extra barriers for racialized parents to access needed services [8].

Only recently has research at the intersection of race and disability started to emerge. Of the limited research on this topic, it has shown that racialized youth experience differential access to care and/or disparities in health outcomes compared to White youth [9], that racialized parents who have children with disabilities accessing early intervention services face racial disparities [10], and that children from racialized groups experience inequitable treatment when accessing pediatric services [11, 12]. Existing research does not focus on the lived experiences of parents at the intersection of race and disability in a community based pediatric rehabilitation context in Canada, presenting a knowledge to practice gap that may reinforce systemic racist and ableist practices in community, social services, and healthcare [13]. To fill this gap, the following research question was explored: From the perspective of racialized parents, how does race impact the access of services in a community-based pediatric rehabilitation setting?

Methods

Pediatric Rehabilitation in Ontario

Canada has a universal publicly funded healthcare system, known as Medicare, that covers medically necessary hospital, diagnostic, and physician services [14]. Within this system the provincial and territorial governments are responsible for health services within their own jurisdiction [15]. In Ontario, the Ministry of Children, Community and Social Services is responsible for pediatric rehabilitation services for children and youth with disabilities and consists of specialized services (e.g. physiotherapy, occupational therapy, speech and language therapy, therapeutic recreation, behavioural services etc.) but do not cover mental health services [16]. These services are not classified as healthcare, instead it falls under the umbrella of social services where some services are publicly funded, and others are privately subsidized by parents' employment benefits or out-of-pocket finances.

Guiding Theory

To guide this research, intersectionality and DisCrit (Dis/ability Critical Race Studies) theories were used [17, 18]. The concept of intersectionality was first introduced by Kimberly Crenshaw in 1989 to examine the various ways in which race and gender interact to shape the multiple dimensions of Black women's employment experiences and the double-discrimination that they faced [18, 19]. Else-Quest and Hyde found that three main commonalities make an intersectional definition [20]. The first is that intersectional definitions recognize that all people are characterized by multiple social categories that are interconnected or intertwined, that embedded within each of these categories is a dimension of inequality or power and lastly, social categories are properties of the individual as well as the social context and are fluid and dynamic [20] This definition was used to inform the interview guide questions and to guide the analysis in examining the intersections of race and disability within these categories. In addition to intersectionality, a DisCrit approach was used to guide the research, which seeks to incorporate a dual analysis of race and disability [17]. DisCrit aims to address the structural power of racism and ableism by recognizing the broader historical, social, political, and economic factors that shape the experiences of this population [17].

Study Design

A multiple descriptive case study approach was chosen to allow for the exploration of the unique, individualized experiences of racialized parents who have children with disabilities while also examining the similarities and differences between cases using multiple sources of information [21, 22]. This approach allowed for the exploration of the unique, individualized experiences of racialized parents who have children with disabilities while also examining the similarities and differences between cases to further understand the *quintain* [23]. Furthermore, due to the nature of the topic, multiple interviews also allowed participants to become more trusting and comfortable in successive interview sessions, leading to increased rapport with the interviewer [24].

Participants/Recruitment

Eligible participants were racialized parents aged 18 years or older who had a child, or children, with disabilities who were currently accessing services at a pediatric rehabilitation centre located in Ontario, Canada. Racialized was defined as any person who is not White or Indigenous [25] and parents self-identified as racialized before joining the

study. Other eligibility criteria included the ability to speak and read English, access to the internet to join video-conferencing meetings and being a resident in the area where the centre was located. Virtual interviews were chosen to give parents the flexibility and convenience to work around their schedules, remain with their children, and be in a comfortable setting of their choosing.

Three participants were recruited using purposive sampling techniques to recruit racialized parents who had a child with a disability currently accessing services [26]. Recruitment was carried out through social media postings and an information webpage that was connected to the organization where the study took place. The research team also used a family advisory committee which consisted of two racialized parents that had children with disabilities to help recruit participants through word of mouth. A range of stages of children's development (e.g., pre-school aged 2–5, elementary school aged 6–12, and a youth aged 13–18) as well as a variety of disability diagnoses (e.g., physical, developmental, communicative) was captured. Qualitative case study research lacks clear guidelines on the sample size required to reach saturation [27]. The goal in this research was not to capture the entire range of the phenomenon as even large samples may not fully encompass its complexity. Rather, the focus was on a smaller sample size using an information power approach to acknowledge the richness, depth, and diversity of participants insights [28].

Ethics

This study was approved by the Research Ethics Board of the research team (#24-016-D). All participants signed and submitted an informed consent form before enrolling in the study, were given the opportunity to ask questions before the interviews began and were reminded that their participation in this research was voluntary.

Researcher Reflexivity

Before the interviews took place the first author shadowed therapeutic sessions at the centre to observe the environment and gather contextual background information related to pediatric rehabilitation services [29]. The researcher also kept a reflexive journal and engaged in self-reflection to set aside beliefs and assumptions to avoid misrepresenting the experiences of participants [30]. The first author brought both an insider and outsider perspective to the research. As a racialized woman she shared some lived experiences with participants; however as someone who is neither of mixed race or Black descent and does not have children with disabilities, she also approached the study from an outsider perspective [31].

Data Collection

Three semi-structured interview guides were created based on the overarching research question, the literature on this topic, and in consultation with an inclusion, diversity, equity, and accessibility family advisory committee to ensure the voices of the population of interest were represented in the research process [32]. Each racialized parent was interviewed three times by the first author for a total of nine interviews. The first interview aimed to understand the experiences of the parent of a child with a disability, the second interview focused on the service journey of the parent, and the third interview aimed to understand race and its relation to accessing and receiving services. Interviews were conducted approximately one to two weeks apart from each other, were held online at the convenience of the participants, and took place between December 2024 – March 2025. Each interview lasted one hour. Google Meet was the platform used, sessions were recorded, and transcripts were generated which were later deidentified. Pseudonyms were used in place of children's, parents, and clinician names; additionally, all identifying information (e.g., employment, specific locations) were removed to mitigate the risk of re-identification of participants in this study and ensure confidentiality.

After each interview, the researcher sent participants a deidentified transcript, providing each participant an opportunity to request changes they would like, such as additions, clarifications, and omissions [33]. Each participant was later sent an individualized, synthesized member-checking document with preliminary themes and supporting quotes that were generated across the interviews they participated in [33]. This document allowed the participants to engage with the interpreted data through highlighting the text or sending the researcher an email and served as a validation technique to ensure that the findings accurately reflected their experiences. Given the in-depth nature of the study design this form of member checking was important for constructing the cases through the participants personal and lived experiences [33].

Data Analysis

Informed by the multiple descriptive case study design methodology, two levels of analysis were conducted. First, a within case analysis was employed where researchers provide a description of the individual case and themes [21]. To begin, the first author researcher reviewed each transcript multiple times alongside listening to the recordings to become familiar with the overall narrative and engaged in memoing notable themes, quotes, and personal self-reflection [34]. A narrative document of each case was created to generate initial

themes and experiences of each participant. All researchers then discussed the narrative documents, using an iterative process to develop specific subcodes and themes that better represented the experience of the participants. The NVivo 15 coding software was used, and an inductive approach was employed to generate initial codes followed by the creation of themes and codebook [35]. The cross-case analysis then examined which themes were similar across the individual cases which involved reading the individual case reports and multiple meetings between all researchers to decide on the cross-case themes [23]. Investigator triangulation increased the inter-rater reliability of the data across both levels of analysis [36]. Intersectional theory and DisCrit theory were used in the analysis as interpretive lenses to connect participants experiences to broader systemic barriers.

Results

Within Case Analysis

Case 1: Jennifer

Jennifer identifies as a middle-aged mother who is of mixed-race descent, speaks both French and English, is of Agonistic faith, and is a mother of multiple children of different ages, including Max, who is preschool aged. Max was diagnosed with multiple disabilities early in life and is still awaiting potential diagnoses for other disabilities. As a parent of a child with a disability Jennifer has embodied the role of being an advocate for Max. When engaging in advocacy at her local centre she expressed feeling the "*angry Black woman*" stereotype. She shared "*you know*, *if I looked a different way*, *I think that the way that my thoughts would be received would be very*, *very different and I really truly believe that".* Jennifer wears the "*angry Black woman*" label proudly but doesn't want to be seen as the "*crazy Black lady"*. She feels as if her points are valid, and she is willing to wear the label for her son "*…it is worth it for him*."

Case 2: Sarah

Sarah identifies as a middle-aged mother who is of Black and South Asian descent, is of Protestant faith, only speaks English, and is a single parent of her elementary school-age daughter, Sophia. Sophia was diagnosed with autism at age two and a half. Sarah described that having access to a social worker was "*life changing*" as it helped her to fill out paperwork which she found was "*triggering*", and provided her with a resource to discuss her child's diagnosis and instances of racism she experienced in the immigration, employment, and daycare sectors. These experiences have shaped the way she approaches services for Sophia, especially when there is a lack of diversity in programs. In the context of pediatric rehabilitation services, Sarah expressed that she wanted access to communication resources that had culturally tailored vocabulary surrounding cultural foods (e.g., curry chicken) to help Sophia to express her preferences.

Case 3: Ava

Ava identifies as a middle-aged mother who is of Catholic faith, only speaks English, has a disability, and is of Black Caribbean, Caribbean Indian, Cuban, and White descent. She is a single parent of three children, including Emma, who is a teenager and was the primary focus of this interview. Emma was diagnosed with autism around age two and has physical disabilities as well. Ava disclosed that she was separated from her husband after experiencing abuse in their relationship and that despite her best efforts to protect her children; they also experienced abuse from family members and within the school system. Ava's telephone communication was blocked by her ex-husband leading Emma being discharged from services at her local centre. When Ava described her situation to staff members, she felt they lacked awareness and knowledge about abuse and did not feel supported. On top of abuse Ava described experiencing racism in the healthcare system when engaging in advocacy for herself and children stating: "*if we [Black women] want to advocate for ourselves*, *we're being too pushy*, *like we're being angry when we're not even being angry…"* and Black women are treated better if they say, "*nothing at all*".

Cross Case Analysis

Ableism and Formal Diagnoses

One of the barriers to accessing services that parents encountered was the need for a formal diagnosis. Jennifer described that she wished she had an "*avenue to get the diagnosis moving*", and wished she could have received an earlier diagnosis. Sarah described similar feelings having to wait 15 months for a diagnosis while "*knowing*" that Sophia had autism during that period. Ava also experienced barriers trying to get a diagnosis and referrals to services from her family doctor. She explained that her family doctor wasn't screening for autism, had a "*bad outlook on autism*," and because of his cultural views he "*looked down*" on both Ava and her children. When her family doctor later heard about Emma's autism diagnosis from a different physician, Ava described that he had reacted like it was the "*most horrific thing has happened*" and would later ignore faxes and calls for referrals from the pediatric rehabilitation centre.

Parents also experienced judgment and ableism around acceptance before getting their child diagnosed. Jennifer experienced feeling "*gaslighted*" from others, family members telling her "*boys will be boys*," or gossiping about her child and a receptionist telling her that "*older siblings do all the talking"*. Sarah's Caribbean community felt they could "*fix*" Sophia's behaviours or assumed that Sophia is "*bad*" or "*needs licks*" [beating], or "*discipline"* and experienced judgment from other moms in the waiting room at her pediatric rehabilitation centre. Ava was told by family members that her child was not speaking because she was not "*not faithful enough*" and when a family member found out about her doing an assessment, they "*went on a rampage trying to stop it*" and tried to "*bully*" her.

Program Wait Times and Scarcity

Another barrier that parents experienced while trying to access services is the long wait times and the overall scarcity of programs that are available. Jennifer shared that Max will be entering his fourth year of waiting for core clinical services which can consist of programs such as speech language pathology (SLP) or applied behaviour analysis (ABA) through the Ontario Autism Program (OAP). The OAP is a government funded program that provides financial support to families who have children that are diagnosed with autism and currently has an extensive wait time. Jennifer described this waiting period as "*stressful*" and does not know when she will get off the waitlist because this information is not disclosed to parents. When Sarah first began accessing services for Sophia, she described learning that there would be a four to six month wait time as "*frustrating*". Currently, she is waiting for a speech therapist for Sophia, and there has been a four-month break since the last session, with no estimate of when a new therapy block will be available. Ava described that the mental health services also have extremely long wait lists and that there are not enough programs when children age out of pediatric services.

Racialized parents also explained how their race may impact their feelings around wait times. Ava describes feeling that schools give preference to certain children of a certain race to receive a psychological assessment and states that she doesn't "*think that her demographic's going to get it.*" Jennifer also described feeling that race plays a role into accessing programs and expressed that these differences are not overt, but states:

> *When all of the educators are White, and all of the thought leaders are as well, and all of the advocates are as well, and all of the important people look a certain way and communicate a certain way and drive a certain agenda. You know, ultimately, we cater to the masses, right?*

Diverse Service Providers and Representation

Jennifer, Sarah, and Ava all discussed the positive impact that having racialized staff members would have on their experiences accessing pediatric rehabilitation services. Jennifer discussed the impact of having a non-White, male clinician and shared that the experience was "*really positive for working with a young boy*". She expressed that therapeutic sessions are "*a lot of learning"* and having a racialized staff member would help her to feel more comfortable and "*more at ease.*" Sarah voiced similar feelings and shared that having a service provider that is the same race as her would make her feel more "*comfortable*", "*excited*", and want to "*cling towards them*". She also described that she believed they would treat her "*nicer*", and she would feel "*safer going to them."* Ava expressed the importance of having a Black social worker stating: *"it would have done a lot for me to be able to speak to someone who I felt more comfortable with and I felt really understood me more and I wouldn't be as judged".* If she had a Black social worker, she would have gone to the Black woman "*faster*" and "*quicker*" about her abuse compared to a White social worker. With a White social worker Ava would have said "*she helps me with paperwork. She's a nice lady. I better not bother her*" because she didn't want the social worker to think "*bad of her*". Whereas with a Black social worker, Ava may have "*whispered*" her circumstance and if she got positive feedback she would have "*opened up*" more. In addition to racially diverse social workers, Ava also described the importance of professionals who are knowledgeable about religion. Having access to a Black Christian social worker would have helped her family to accept her children's disabilities and would have been something she "*clung to*."

Parents also discussed how having racialized staff members is important for representation. Jennifer described wanting her regional centre to be an "*environment where she recognizes herself"* and shared *"I want to see you know, people look like me, who sound like me, who have kids who have challenges like mine, and maybe someone with a mobility issue, maybe somebody with a disability…".* Sarah also shared how representation impacted her child where she observed that Sophia will point out that a therapist is Black, or ask whether a new therapist is a "*Black or White lady*?" Sarah suggested that these comments may reflect Sophia's awareness of being part of a "*minority*" population as well as her recognition of the diversity that is present, or not present.

Support Groups

Across all the cases, the parents voiced that they wanted access to diverse cultural support groups; or access to groups that they identify with. Sarah described that she is currently

not part of her local centres support group and instead sought out "*Black mom support groups for children on the spectrum*" online. She "*didn't feel comfortable joining the other groups*" as there may be instances of racism she is experiencing and if amongst a group of people that look like her, she doesn't have to explain why she is being "*held back.*" If there was a Black parent support group that was offered at her local centre, she would want to join because it would make her "*feel comfortable around people of a similar experience and cultural background*" and *"they'd understand*" her better. Jennifer shared that the formation of a cultural support group at her local centre would allow her to form a community and feel less isolated. She feels that the current groups at her local centre lacks diversity and states, "*…I just feel like it's just a group that doesn't look like me or talk like me or sound like me or think like me.*" Ava also shared that a Black faith-based group would be very important as sometimes faith can have a higher priority over someone's race, meaning that faith-based support can be beneficial to support some families.

While cultural support groups would be of interest to all three parents, Ava appreciated that the support groups she participated in were not separated by race or culture because she "*needed to see it wasn't a Black thing.*" Through the diversity of the support group, she was exposed to different populations that *"could be in worse circumstances and better circumstances…"* and still collectively be going through the journey of having a child with a disability.

Discussion

The Impact of Racism

Parents in this study described the impacts of racism in both the therapeutic environment and in broader areas of their lives, affecting the way they approach and access pediatric rehabilitation services. They each provided an example of three levels of racism: institutional, personally mediated, and internalized [37]. Institutional racism can create barriers for racialized parents trying to seek a diagnosis for their child. Previous research has shown that Black children receive a later diagnosis for autism than White children and require three or more visits to receive a diagnosis [38, 39]. Service providers may be interpreting the child's behaviours differently, assuming that racialized populations are more disobedient, aggressive, or violent, leading to differences in diagnosis compared to White populations [40]. Experiences of institutional racism can lead to barriers and differential access to care, potentially affecting the outcomes of the child and the services they are able to access. The extra layer of looking for diverse programs creates additional challenges while trying to navigate a complex system highlighting the need for pediatric rehabilitation clinics to address these biases.

Personally mediated racism was demonstrated through stereotypical assumptions about parents. The "angry Black woman" stereotype presumes all Black women to be "irate, irrational, hostile" where Black women who display their anger due to social, political, and economic injustice, are perceived as "unfeminine" and "unacceptable"[41 p.29]. Jennifer expressed that she wears this "*label proudly*" which can be reclaimed as a source of empowerment and resistance to being treated unfairly and fight back against societal barriers [41]. At the same time, these perceptions can affect provider-client relationships as racialized parents are "*pushed away*" or viewed by staff as a "difficult" parent. This hinders the ability for racialized parents to access services they need for their children and can lead to less attentive care, avoidance from providers, or the inability to access referrals for further resources.

On the other hand, the "angry Black woman" stereotype may lead to Black women to internalize the racism and suppress their emotions to obtain acceptance from society, negatively affecting their self-worth and personal feelings [42]. This suppression can lead racialized parents to withdraw from advocacy for their child, meaning racialized children with disabilities might not have access to the same opportunities or services that they need. When racialized parents feel they are being stereotyped, or unheard, in an environment that is supposed to be a safe space for their child they may also start to avoid accessing pediatric rehabilitation systems completely, leading to unequal health and developmental outcomes. There is a need for service providers to be aware this may be occurring and actively take steps to identify and address and these experiences.

Interpreted through an intersectional lens, the participant narratives demonstrate the intersecting layers of gender, race, and disability and the impact it may have on racialized parents accessing pediatric rehabilitation services. Racialized parents face an additional layer of racism in the advocacy environment and are met with resistance while trying to access services for their children [10]. Racism is not a universal experience among parents, instead it is complex, multifaceted, and threaded throughout their lives [43].

Perceived Racism

The broader experiences of racism that parents experienced in different areas of their lives not only affect the way that they make decisions about their children's care, but how they approach the therapeutic environment and their thoughts and feelings about waitlists [44]. Exposure to racism and racial bias from interactions with employers, the criminal justice system, the medical system, the education

system, or other institutions can lead to perceptions of being exposed to racism even when the direct interactions with members of these institutions (e.g., supervisors, police officers, doctors etc.) may not have been directly or overtly discriminatory [44]. While a universal experience of parents that have children with disabilities accessing pediatric rehabilitation services are wait times [45], due to the multiple different instances of racism that families in this study experienced, their perception of waitlists and access to services may be influenced by their broader racial experiences, meaning that racialized parents may be coming to the therapeutic environment with the perception they may be treated differently.

These feelings of being treated differently when accessing or waiting for services can lead to medical mistrust [46]. Previous studies have shown that medical mistrust was higher amongst populations with higher levels of perceived discrimination and experiences of racism are associated with lower perceived quality of care [47]. This may lead racialized parents to distrust the pediatric rehabilitation services they are receiving, the programs they are accessing, and question the fairness and ability of these institutions to provide unbiased care [48]. Based on these findings pediatric rehabilitation centres can improve their communication about programs and wait times to be more transparent to help improve trust.

The Impact of Ableism

For racialized parents they experience a "double burden" [49]of judgement with their children being judged because of their race as well as their child's disability facing a lack of support from within and outside of their communities. Parents described experiencing all three levels of ableism: institutional through the systematic denial of resources and opportunities; personally mediated or discrimination between individuals; and internalized where negative stereotypes are accepted [50]. The inadequate training, knowledge, and support in medical schools about disabilities like autism [51, 52] may be contributing to the lack of screening. When combined with cultural views or personal attitudes around disability this can lead to additional barriers for families accessing pediatric rehabilitation services because doctors can be gatekeepers to these services.

Participants in this study also experienced personally mediated ableism [53]. Parents of children with disabilities report judgement from others because people do not understand their child's behaviours [54] but for racialized parents that have children with disabilities, cultural views on disability may add to ableist beliefs with some cultural communities viewing disability as shameful, place pressure on the parent to hide the child's disability, and blame the parent for the child's behaviours [55]. The judgment can also go beyond the parent and impact the racialized child, leading them to internalize the ableism potentially affecting their willingness to approach the therapeutic environment [56]. Racialized parents may internalize these comments leading them to feel the need to ensure their child assimilates to "acceptable" societal norms. These experiences can not only affect comfort levels of racialized parents when they are accessing services but can add to the mental load of planning and preparing their child before going to services.

From a DisCrit perspective, the findings highlight that the intersection of race and disability is multifaceted and experienced from the disability, non-disability, and cultural communities; often leaving parents with very limited areas of support. While the parents in this study were all connected with the children's treatment centre, the literature reports that some children do not receive the treatment or intervention they need due to parent denial, stigma, or a lack of acceptance in their communities [57]. These findings demonstrate the need for service providers to be aware of the broader cultural barriers that racialized families may be experiencing when accessing or trying to access services to provide more support or resources for these families. It also highlights the need for cultural training not only within pediatric rehabilitation centres but also various institutions (e.g., medicine) to reduce service gaps, improve communication, and overall awareness on judgement, ableism, and stigma.

Importance of Diverse Service Providers

When racialized patients have access to providers who are of the same race as them it leads to enhanced communication, higher perceived quality of care, enhanced cultural understanding, comfort, safety, and relatability, which is similar to the findings in this study [58]. In healthcare settings, physicians may lack understanding of parents ethnic or cultural backgrounds which is why racialized patients prefer someone of the same race to share cultural values, beliefs, and experiences in society allowing for more effective communication and comfort [58]. Although all participants were able to speak English as a first language, diverse service providers can also help with communication barriers and potentially facilitate the incorporation of cultural communication resources (e.g., communication boards/cards) in different languages for various racialized groups. Access to diverse service providers may also help with acceptance of the disability as providers may have knowledge of certain cultural practices/beliefs, helping to increase communication between service provider, parent, and family members [58]. As seen in these findings from a DisCrit and intersectional viewpoint representation is not only of importance to the parent, but also to the child who looks for representation of their own race and familiarity in

who is providing them therapy to reduce the compounding effects of racism and ableism. The incorporation of diverse service providers can have positive effects for both racialized parents and children highlighting the importance of this intersection in this environment.

Strengths and Limitations

No study is without its limitations. Virtual interviews may not allow for rapport to be built between the researcher and the participant and may have excluded those who do not have access to this technology. Self-selection bias could have been present, where participants who joined this study may have been more open to and interested in the topic [59]. Additionally, all participants were required to speak English preventing us from potentially understanding some cultural elements of participants that do not speak English. Participants were recruited from one organization, limiting our understanding of the stigma parents may experience when waiting for or accessing services. A strength of this study was the depth of the data that was collected through the successive interviews allowing us to understand the lived experiences of racialized parents that have children with disabilities. This study also provided insights into the developmental stages and needs of children at difference ages of their life.

Recommendations for Future Research

First, because the primary focus in this study was on race and disability and our sample was small, other critical intersections such as parents from LGBTQIA2S+ communities, newcomer populations, non-English speakers, fathers, or parents of different religions/faiths should be explored in the future. Second, the population consisted of mostly mothers, who do not themselves have disabilities, and are instead accessing services for their children with disabilities. Finally, given that two out of three parents highlighted the importance of social work, more research is needed to understand the potential importance of this service for racialized families, specifically, while accessing pediatric rehabilitation services.

Conclusion

While racism is ingrained and woven into our systems, so is ableism; and viewing these findings through an intersectional and DisCrit lens, have unveiled additional barriers for racialized families and their children [17, 18]. Community based pediatric rehabilitation services should incorporate culturally tailored resources, care, and diverse staff to ensure that parents and their children feel safe, comfortable, and represented. To reduce feelings around perceived racism, it may be helpful for centres to publicly disclose all the information around how the waitlists work, what are the expected wait times, and ensure that all the information is explicitly clear and transparent to reduce the ambiguity associated with waiting. Lastly, since parents expressed that they experience a range of barriers and inequities outside the therapeutic environment it is important that centres to take into consideration broader inequities to better understand the influence that systemic barriers may have on families attending appointments as well as provide enhanced resources and support.

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Author Contributions Alissa Latiff completed this work as part of her master's thesis. She collected the data, analyzed the data, and wrote the manuscript under the supervision of Dr. Meghann Lloyd who is a Co-PI on the funded grant. Dr. Lloyd collaborated on all stages of the research including the conceptualization of questions and interpretation of results and editing the document. Dr. Taryn Eickmeier was a committee member of Alissa's and a Co-PI on the funded grant; she reviewed the interview guide, the results, the final document before publication.

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Data Availability Due to the case-study methodology, and the required research ethics obligations to prevent re-identification of the small sample the raw data is not available.

Code Availability Not applicable.

Declarations

Ethics approval This study was approved by the Research Ethics Board of the research team (#24-016-D).

Consent for Publication Participants provided consent for publication.

Consent to Participate All participants signed and submitted an informed consent form before enrolling in the study, were given the opportunity to ask questions before the interviews began and were reminded that their participation in this research was voluntary.

Competing interests The authors report there are no competing interests to declare.

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