How Discrimination Shapes Care-Seeking for Black Caregivers of Children With Medical Complexity

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abstract

OBJECTIVES: Black children with medical complexity (CMC) experience a disproportionately high number of hospitalizations and emergency department (ED) visits. This disparity may reflect systemic and interpersonal racism and discrimination. Understanding Black caregivers' experiences is essential to designing programs that reduce acute care use. This study described caregivers' experiences of racism and discrimination and explored how these experiences influence care-seeking and communication among Black caregivers of CMC.

METHODS: In partnership with family advocacy organizations, we recruited Black caregivers of CMC via national advocacy groups, social media, and electronic health record messaging. Eligible caregivers had a child aged 0 to 21 years with a hospitalization or ED visit in the previous year and a score of 3 or more on the Children with Special Health Care Needs screener. Purposive sampling ensured that one-third of participants were from rural areas. Semistructured interviews, guided by Critical Race Theory, were recorded, transcribed, and analyzed thematically.

RESULTS: Thirty-one caregivers completed interviews. Caregivers described discrimination in health care based on race and other characteristics. Five themes emerged in caregivers' experiences of racism: dismissal, stereotyping, fear of retaliation, dehumanization, and differential access to resources. These experiences contributed to distrust, caregiver burnout, and perceived negative health outcomes. Caregivers' responses to discrimination included withholding concerns, advocating, documenting, selecting specific clinicians, managing perceptions, and staying informed.

CONCLUSIONS: Perceived racism and discrimination shaped how Black caregivers of CMC communicated with clinicians and navigated health care, underscoring the need for health care systems and clinicians to foster trusting partnerships, address structural inequities, and provide equitable, family-centered care.

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A Nmoh contributed to study design, conducted study recruitment, conducted and analyzed qualitative interviews, contributed to interpretation of findings, led development of the initial manuscript, and critically reviewed and revised the manuscript and study materials. J Rodriguez coordinated and conducted study recruitment and critically reviewed and revised the manuscript and study materials. LJ Fish, HE Parnell, and C Makarushka coded interviews, led data coding and analysis, and critically reviewed and revised the manuscript. B Leach, C Moore, T Miles, and L Powell assisted in the conceptualization and design of the study and study recruitment and critically reviewed and revised the manuscript and study materials. L Baumgardner and V Parente assisted in the conceptualization and design of the study and critically reviewed and revised the manuscript. (Continued)

WHAT'S KNOWN ON THIS SUBJECT: Black children with medical complexity experience disproportionately high rates of hospitalizations and emergency department visits. Systemic and interpersonal racism and discrimination may contribute to these disparities, yet caregiver perspectives on how racism and discrimination shape care-seeking and communication remain underexplored.

WHAT THIS STUDY ADDS: Black caregivers described perceived racism and discrimination in health care as pervasive and shaping trust, communication, care-seeking, and perceived outcomes. Caregivers highlighted the need for health care systems to foster trusting partnerships, address structural inequities, and provide equitable, family-centered care.

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INTRODUCTION

Children with medical complexity (CMC) are a subset of children and youth with special health care needs (CYSHCN) who have severe chronic conditions, functional limitations, and high health care use.[1] CMC account for 40% of US pediatric hospital days.[2,3] Black CMC insured by Medicaid have a disproportionately high frequency of hospitalizations and emergency visits, a disparity reflected in multiple studies of Black children with chronic diseases, regardless of insurance type.[2–6] The drivers of higher acute care use among Black CMC remain unclear yet are important to elucidate as health care systems and insurance payers seek to reduce hospitalizations.

Previous studies show that Black patients experience ineffective communication, guideline-discordant care, and barriers accessing medical resources.[7–12] CMC and their families also contend with the challenges of navigating poorly coordinated care, health care clinician discomfort caring for CMC, and discrimination because of disability.[7,8,13–17] Thus, Black CMC experience synergistic risk factors for poor health outcomes.

The objectives of this study were to describe Black caregivers' experiences of racism and discrimination and explore how these experiences, if present, influence how Black caregivers seek care for their CMC and communicate with health care professionals.

METHODS

Study Design

This study was the result of a community-academic partnership between pediatricians and national family advocacy organizations. We conducted semistructured interviews with Black caregivers (ie, parents, guardians) of CMC. All participants provided informed consent, and the study was approved by the Duke Health Institutional Review Board. This study was conducted and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research.[18]

Recruitment

Caregivers were recruited through advocacy organizations, clinics, and Duke Health electronic health record messaging. Caregivers were provided with study information and interested individuals were subsequently screened via phone. To be eligible for the study, caregivers had to identify as Black or African American, be a parent or guardian of a child aged 0 to 21 years with at least 1 hospitalization or ED visit in the previous year and a score of 3 or more on the CYSHCN screener.[19,20]

Recruitment was guided by the principle of information power, with the goal of obtaining sufficiently rich data to address our research questions.[21] We established an a priori recruitment target of at least 30 participants based on previous studies.[7,22] We also used purposive sampling to ensure at least one-third of caregivers lived in rural areas (rural urban commuting area code code >1) and one-third had a child who used medical technology (eg, feeding tubes) as these factors influence health care use.[2,23,24] Recruitment concluded once we achieved the a priori recruitment target, met purposive sampling goals, and reviewed transcripts demonstrated sufficient depth and relevance to address study aims.

Study Framework and Definitions

Critical Race Theory Public Health Praxis (CRTPHP) was the primary study framework (Table 1).[7,25] For this study, we defined racism as "being treated worse than another person because someone sees you as a member of a racial group" and discrimination as "someone treating you worse than another person because of another characteristic other than race."

Interview Guide

Guided by CRTPHP, we developed an interview guide similar to a previous study of adult patients with chronic diseases.[7,25] The interview guide consisted of 3 sections (Supplement 1): (1) perceived direct and vicarious (ie, experienced by a friend/relative) experiences of racism and discrimination in health care and their impact on care-seeking and communication; (2) opportunities to improve caregiver-clinician communication; and (3) caregivers' needs and preferences for interventions. Although interview questions focused on health care experiences, some caregivers described discrimination outside of health care. Because these experiences may influence how caregivers navigate the health care system, they were included in data analysis.[26]

The interview guide was reviewed by caregivers of CMC, health care professionals, and qualitative research experts to ensure questions were appropriate and aligned with study objectives. We also piloted the interview guide with 3 Black caregivers of CMC to ensure question clarity before proceeding with further data collection. Given no significant changes to interview questions, pilot interviews were included in data analysis.

Data Collection and Interviews

We collected participant demographic data via survey. Semistructured virtual interviews were conducted between November 2024 and May 2025 by 2 racially concordant individuals, AN and MW. AN is a female medical student with significant qualitative research experience. MW is a female pediatric hospitalist with expertise in qualitative research. Interviews were 60–90 minutes, audio recorded via Zoom, and transcribed by a professional transcription service. Caregivers were compensated $70.

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TABLE 1. Application of Principles of Critical Race Theory to Centering Black Voices

Principle	Definition	Application
Primacy of racialization	Racial stratification is central to societal inequity	• We designed the study to assess the influence of racism on care-seeking and communication. • During data interpretation we recognized that racial hierarchies exist within and beyond the medical system, including between Black patients and their clinicians, exacerbated by the underrepresentation of Black health care professionals. Our discussion of retaliation is one example.
Race as a social construct	Race is not biological but the product of social, political and historical forces	• During study conceptualization we recognized Black CMC and their caregivers as a population at risk for experiencing racism and discrimination due to social, historical and political forces. • We used purposive recruitment to recruit caregivers of diverse backgrounds, including rural and urban caregivers, because experiences of racialization and racism vary.
Ordinariness of racism	Racism is ubiquitous in society	• We constructed our interview guide with the understanding that racism is a common experience for both Black CMC and their caregivers. • We examined both vicarious and personal experiences of racism because racism is common, and its impacts extend beyond personal experiences.
Race consciousness	Awareness of one's racial position and racial stratification in society	• We had racially concordant interviewers to facilitate participants' comfort sharing personal experiences. • We are a multiethnic team of community members and health care professionals, and the team regularly discussed and acknowledged their identities and biases in health care and in the community.
Social construction of knowledge	Established research can be re-evaluated with antiracist methods	• Although there is a strong body of literature describing CMC, there is a paucity of data describing the influence of racism on health outcomes in CMC. Rather than take this as evidence that racism was an insignificant factor, we developed study objectives that would allow us to identify the influence of racism and opportunities to render current programs for CMC more equitable.
Intersectionality	Individuals contain co-occurring identities and experience social stratification based on 1 or more identities	• Interview questions addressed racism and other forms of discrimination (eg, gender, disability, income), reflecting how intersecting identities shape experiences of discrimination and privilege. • Interpretation of study findings emphasizes different types of bias experienced beyond racism.
Disciplinary self-critique	Reassessing a discipline's norms and how they might contribute to health disparities	• The project was conceived and conducted as a community–academic partnership. Team members outside of academic medicine and health care were encouraged to question methods, norms and hierarchies common in academic research that might contribute to disparities. For example, caregivers' experiences and preferences resulted in critical examination of disciplinary norms for patient care and communication.
Voice	Privileging the perspectives and contributions of marginalized groups	• During data collection and interpretation, we intentionally centered and validated the experiences of Black caregivers. • We used member checking with caregivers after interviews were completed to ensure our findings accurately reflected the perspectives of Black caregivers of CMC.

Abbreviation: CMC, child with medical complexity.

Data Analysis

Qualitative analysis was led by 3 experienced qualitative analysts (LF, HP, and CM). LF, HP, and CM are white women with graduate degrees; LF is the parent of a CMC.

Interview data were analyzed using NVivo software and a staged thematic analysis approach.[27,28] The analytic team (LF, CM, HP) created an initial codebook based on study objectives, CRTPHP, and review of transcripts. After independently applying the initial codebook to 3 transcripts, they met to qualitatively assess interrater agreement, resolve coding discrepancies, and modify code definitions. An additional 5 transcripts were double-coded for a total of 25% (n = 8). The remaining transcripts were single-coded. The 3 coders met weekly to assess coding reliability and iteratively refine the codebook by incorporating additional deductive codes informed by interview content and team discussions (Supplement 2). Analysts used memoing to capture coding questions, decisions, reflections, and emerging interpretations.[29]

MW and AN met monthly with the analytic team to guide interpretation. In the final stage of analysis, MW, AN, and the analytic team summarized codes, identified major themes, and selected representative quotations for each theme. The analytic team frequently reflected on their own identities and biases and how they might affect data interpretation.

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Preliminary findings were member-checked by sharing a lay-language summary of results with all participating caregivers, inviting feedback via email, phone, or video call. Member checking did not result in revisions, as participants who provided feedback affirmed study results.

RESULTS

Participants

Thirty-one Black caregivers participated; 94% were mothers, 45% were married, 35% lived in rural areas, and 32% cared for CMC with medical technology (Table 2).

TABLE 2. Participant Demographics

Variables	Frequency N (%)
Relationship to CMC	
Mother	29 (94)
Father	2 (6)
Age, years	
20–39	13 (42)
40–60	17 (55)
Age of CMC, years	
0–10	18 (58)
11–21	13 (42)
Location	
Urban	20 (65)
Rural	11 (35)
Education level	
Some college, no degree	8 (26)
Associate degree	6 (19)
Bachelor's degree	8 (26)
Master's degree	8 (26)
Professional or doctoral degree	1 (3)
Employment status	
Employed	26 (84)
Unemployed (looking for a job)	1 (3)
Homemaker/stay-at-home parent or caregiver	1 (3)
Retired	2 (6)
Unable to work (disabled)	1 (3)
Marital status	
Single	12 (39)
Married or in a domestic partnership	14 (45)
Widowed	2 (6)
Divorced or separated	3 (10)
Household income	
Less than $40 000	8 (25)
$40 001–$60 000	6 (19)
$60 001–$80 000	6 (19)
More than $80 001	10 (32)
Number of adults in household	
1	10 (32)
2	16 (52)
≥3	5 (16)
Number of children in household (including CMC)	
1	8 (26)
2	10 (32)
≥3	13 (42)
Home nursing	
Yes	4 (13)
Medical technology use	
Yes	10 (32)

Abbreviation: CMC, child with medical complexity.

Participants represented a diversity of education and household incomes and resided in the southern United States (Georgia and North Carolina).

Caregiver Experiences of Racism

Across interviews, caregivers described direct and vicarious experiences of racism in health care operating through themes of dismissal, stereotyping, retaliation, dehumanization, and differential access to resources (Table 3).

Dismissal

Caregivers felt their concerns about their CMC were often dismissed or diminished by health care clinicians because of their race. Some caregivers described having to repeatedly raise the same concern before action was taken. Others felt they had to escalate concerns to hospital administrators or seek second opinions to ensure their child's needs were addressed. Overall, caregivers felt health care professionals did not value their expertise or knowledge of their child. One caregiver shared: "I felt dismissed, like I was making stuff up... as if it was just nothing" (Caregiver 30).

Stereotyping

Many caregivers believed that racial stereotypes affected the care they received. One caregiver stated: "It's like they have put us all in a box" (Caregiver 17). Caregivers shared experiences where clinicians assumed they were negligent, using illicit substances, or physically abusive when their CMC presented with problems related to underlying medical conditions. Caregivers perceived that they were viewed with suspicion rather than trust. Some described

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TABLE 3. Caregiver Experiences of Racism and Discrimination

Subtheme	Examples
Racism	
Dismissal	• **"**I just feel like most times, you know, you're not being taken seriously. You know, you're just brushed off… so it feels like your concerns are not valid." (Caregiver 12, Caregiver of a CMC aged 7 years) • "I would tell them this is what's taking place… the nurse would literally stare me down and was like, 'No, this can't be happening.'… it's like, they hear you, but they don't hear you." (Caregiver 17, Caregiver of a CMC aged 9 years)
Stereotyping	• "'Well, are you sure he didn't get into anything else?'… are you sure that there isn't something in your home that, you know, maybe shouldn't be there that he touched, or that he, um, ingested?'… Every time it was the same line of questioning, the same treatment like I had done something to him." (Caregiver 3, Caregiver of a CMC aged 17 years) • "A lot of doctors think that I'm uneducated because I'm Black. So, when I ask for a specific document or, um, I want statistics or codes or anything, um, they try to pass me off… I was told by one doctor that, 'I didn't give you the information because I didn't think you would understand it.'" (Caregiver 27, Caregiver of a CMC aged 17 years)
Retaliation	• "When you ask a question, you should not feel like somebody's going to retaliate. And that's how I have felt." (Caregiver 9, Caregiver of a CMC aged 13 years) • "[The doctor] was down talking to me like I didn't know what I was talking about, calling me crazy and things… didn't wanna listen to me when I had different concerns about things going on… And then when I started complaining to him and reported him to State Board… he called CPS on me… told CPS I was neglecting my son." (Caregiver 21, Caregiver of a CMC aged 21 years)
Dehumanization	• "My daughter wanted to come and sit in her lap. And she kind of did a face… a real ugly face, then pushed her… like she was just disgusted." (Caregiver 9, Caregiver of a CMC aged 13 years) • "She said, 'Oh, your skin. It's so rough and tough.' And she kept jabbing her with the needle… 'Her skin is like leather.'" (Caregiver 3, Caregiver of a CMC aged 17 years)
Disparities in access to resources	• "It's like, just the way the information is delivered or not delivered. Given or not fully given. Um, you're redirected to certain facilities and not sent to the best. You know, that's where I've experienced most of, um, the racism." (Caregiver 18, Caregiver of a CMC aged 13 years) • "They didn't give me any resources at all. And so, when I looked in the groups of the other parents like on Facebook groups, some of them that did not look like me doted on like the care there and how they were so resourceful and how they gave them all the [resources] and I was like… Not for me. That was not my experience." (Caregiver 30, Caregiver of a CMC aged 15 years)
Discrimination	
Medicaid bias	• "The norm is for when you have individuals on Medicaid, um, and Black… the treatment strategies that you have don't have to be that sophisticated. It's just enough to get by." (Caregiver 16, Caregiver of a CMC aged 12 years) • "They discriminate instantly of where they will send her, refer her, or if they'll even give her certain tests just because the doctor who's not educated in insurance thinks that [Medicaid] means this person is poor." (Caregiver 27, Caregiver of a CMC aged 17 years) • "I feel like… if I had more money to put in their face about it, then things would've been better for him. But because … we are a low-income family… [doctors] didn't really see a purpose in trying to figure things out." (Caregiver 31, Caregiver of a CMC aged 7 years)
Sexism and single person bias	• "I've seen having a conversation, say with my husband present, gets a different response than me, by myself… it's made me wonder how much weight my word had until, like, my husband speaks up." (Caregiver 25, Caregiver of a CMC aged 7 years) • "Um, being a, um, Black woman with lots of tattoos, young, and, um, unmarried, I think that it—I had to work harder to get people to take me serious even though I've always been a serious parent." (Caregiver 1, Caregiver of a CMC aged 7 years) • "After her mom passed… I felt discriminated against in a lot of ways, because every time I needed to bring my daughter to the hospital… I got a DFCS case every single time… when I brought it up to the lady attention, she was like, 'Well, she's a young lady, so she needs extra supervision,' and I'm like, 'I'm her father, though… and you don't believe that when God created man and woman, he made both equally capable of taking care of the children?'" (Caregiver 26, Caregiver of a CMC aged 17 years)
Ableism	• "She was pulling on her ear… I took her to an urgent care… And they refused to see her because of her medical complexity. And I'm like she has an ear infection. Can you just check her ear?" (Caregiver 7, Caregiver of a CMC aged 3 years) • "Just 'cause he can't walk, he not supposed to have on shoes?…' 'Oh, his skin is so nice.'.. Like, What do you expect?… Do you think 'cause I'm Black… because he has special needs, like I'm not gonna take care of him?" (Caregiver 6, Caregiver of a CMC aged 13 years) • "I got to sit here and explain to you and prove to you, because of his physical limitations, like… why we're here… I shouldn't have to do that. If I sit and tell you his head hurt, his head hurt. Don't ask me, 'Well, how do you know his head hurt?'… that's other type of form of discrimination that we experience… because of his physical disabilities." (Caregiver 16, Caregiver of a CMC aged 12 years)

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TABLE 3. Caregiver Experiences of Racism and Discrimination (Continued)

Subtheme	Examples
Perceived consequences of racism and discrimination	
Distrust	• "I am very reserved… I'm on guard. Because how do I know that what you saying is not just because I'm Black? Or that you have my best interest at hand?" (Caregiver 31, Caregiver of a CMC aged 7 years) • "Am I a burden? Or am I somebody that they think deserves quality care? Um, am I actually being listened to and respected… Or, um, are the notes gonna say something that would make me cry if I had an opportunity to see them?" (Caregiver 5, Caregiver of a CMC aged 10 years) • "I called a virtual helpline… I couldn't get out of bed. I wasn't eating… And she called social services when she hung up with me… Child services came and took my kids… That's why I no longer see a therapist, I don't call any helpline. I seek zero help because I have that fear… I can't tell you the truth." (Caregiver 27, Caregiver of a CMC aged 17 years)
Caregiver burnout	• "I'm the driver in this bus. But I don't want to drive the bus. I want to get on the bus, and you send me to where I need to go. I don't want to feel like I'm fighting all the time." (Caregiver 18, Caregiver of a CMC aged 13 years) • "I don't wanna be a strong Black woman. I'm weak… I need some help… we're looked at as like we supposed to just be strong and know it all, and we don't." (Caregiver 7, Caregiver of a CMC aged 3 years) • "Like that's why I have an expression: 'I have to put on my armor to do this' and that's not how it's supposed to feel when you're looking for health care, right? You're supposed to be like, 'I'm going to get help for my child.'" (Caregiver 18, Caregiver of a CMC aged 13 years)
Delayed diagnosis and increased acute care use	• "I'm telling them his body is rejecting this medication… we had to go through so many ED visits before the doctor say, 'Hey, I heard you guys were in the ED again. I don't think [the medication] is working.'" (Caregiver 28, Caregiver of a CMC aged 10 years) • "I tell the doctor… 'she's not trying to stand. She's not crawling.'….that doctor didn't listen to me at all… then we find out her left hip had been out of socket since she was born. Something that could have been fixed at 6 weeks… And here my baby at 5 years old having to have her hipbone shaved… something that could have been resolved if you just had listened to me and my concerns." (Caregiver 24, Caregiver of a CMC aged 13 years) • "They thought that I was physically hurting my child… my son nearly lost his life before something was actually done." (Caregiver 28, Caregiver of a CMC aged 10 years)

Abbreviations: CMC, child with medical complexity; CPS, child protective services; ED, emergency department.

microaggressions that felt rooted in stereotypes, such as clinicians expressing surprise that their children were "clean" or well cared for.

Caregivers also perceived that clinicians assumed they were uneducated, which they believed led clinicians to withhold medical information or communicate with condescension. Caregivers with professional degrees reported that disclosing their education sometimes shifted how clinicians treated them, suggesting that assumptions about caregiver competence were present initially. Mothers also described being stereotyped as "angry Black women" when they expressed concern, asked questions, or advocated for their child.

Retaliation

Many caregivers feared retaliation from health care clinicians when they asked questions, advocated for their child, or challenged a treatment plan. Perceived retaliatory behaviors included clinicians becoming defensive when questioned, making them wait longer to be seen, calling security, or contacting child protective services (CPS). As one caregiver shared: "My mind always goes to retaliation. Like the next time, am I gonna be treated like the troublemaker?" (Caregiver 2).

Dehumanization

Many caregivers perceived they were treated with less respect and compassion than families of other races, sharing experiences of clinicians entering rooms without greeting them, touching children without introduction, or handling their children roughly. One caregiver stated: "They don't consider us to be human" (Caregiver 16). Several felt their children received less patience and pain control than white children, and some reported that affectionate behaviors (eg, hugs) from their children were met with disgust or labeled as inappropriate. A few caregivers observed greater clinician warmth and kindness toward white families receiving care in the same clinical area, reinforcing perceptions of differential treatment based on race.

Disparities in Access to Resources

Caregivers perceived that information about resources for CMC was often shared through informal networks, with only the well-connected gaining access to beneficial programs and referrals. Black caregivers perceived they had less access to this information than caregivers of other racial groups with one caregiver noting: "The white patient gets more information than the Black patient" (Caregiver 9).

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Several reported observing non-Black families receive more guidance and support from clinicians, reinforcing perceptions that they received less support because of their race.

Caregiver Experiences of Discrimination

Although several caregivers reported experiencing racism exclusively, most described being treated differently based on multiple aspects of their identity, including their Medicaid insurance, perceived marital status, gender, age, or child's disability (Table 3). One caregiver shared, "I can't take my skin off" highlighting the difficulty of distinguishing differential treatment based solely on race vs other factors of identity (Caregiver 1).

Medicaid Bias

Caregivers perceived that children with Medicaid insurance received only "*bare minimum*" care compared with children with private insurance, including more limited evaluations and restricted access to brand-name medications. Some caregivers felt clinicians assumed they could not afford out-of-pocket costs, leading to medical decisions that prioritized lower-cost options without shared decision-making.

Sexism and Single-Person Bias

Married mothers reported that they were treated with more respect and credibility when accompanied by their spouse to health care encounters whereas single mothers noted that attending appointments without a partner made them more prone to dismissal. Fathers, by contrast, experienced dismissal whether married or single. Multiple mothers reported that health care clinicians often looked to mothers to validate fathers' concerns, and one father reported that his concerns were often dismissed.

Ableism

Caregivers reported being refused care in certain facilities because of their child's condition. They often had to advocate for accommodations, particularly for children with less visible disabilities, and for appropriate treatment goals. Those speaking for nonverbal children felt their knowledge and assessments were frequently questioned. Ultimately, many felt clinicians did not consistently partner with them to fully evaluate and support their children's unique potential.

Navigating Racism and Discrimination in Health Care

In response to experiences of racism and discrimination, caregivers employed strategies to navigate the health care system and communicate with clinicians (Table 4).

Advocating and Following Instincts

Over time, many caregivers became more direct in expressing concerns, seeking explanations, and requesting referrals and evaluations. They learned to trust their instincts, confronting clinicians when they felt dismissed. One caregiver shared "[Experiences of discrimination] made me like a straight shooter… 'This is what [child's name] needs... Give it to her'" (Caregiver 7).

Being Informed

Nearly all caregivers highlighted the importance of being informed. They perceived they could not rely on the health care system to provide relevant health information and resources to Black families. Thus, caregivers became experts on their child's condition and actively sought knowledge from other caregivers, online resources, advocacy organizations, and social media. Many intentionally learned and used medical terminology to counter stereotypes and strengthen their credibility with clinicians.

Documenting

Caregivers described preparation and documentation as essential for advocacy and accountability. Caregivers prepared for appointments by compiling questions and maintaining detailed medical records to support their advocacy and reduce dismissal. Many documented health care interactions to ensure accountability, follow up on requests, and report negative experiences. One caregiver shared, "Medical professionals sometimes are just so dismissive... documentation goes a long way because now you're holding that medical professional accountable" (Caregiver 16).

Managing Perceptions and Holding Back

Caregivers described entering health care encounters aware of stereotypes about Black caregivers and intentionally managing their tone, body language, emotional expression, and appearance to counter them. They suppressed anger or frustration due to fears of being perceived as "difficult," and some "held back" concerns when they felt dismissed, framing this not as passivity but as a deliberate strategy to preserve credibility, protect their child's access to care, and avoid retaliation or further dismissal. Several caregivers also believed that being well-dressed and well-groomed reduced the likelihood that they or their children would be dismissed. One caregiver shared: "I feel like Black kids have to look a certain way to be treated well" (Caregiver 1).

Protecting, Selecting Clinicians, and Self-Care

Caregivers described protective strategies to safeguard themselves and their children while navigating health care. Several remained physically present at all times during hospitalizations, procedures, and therapies because previous adverse health care experiences heightened concerns about physical and psychological harm from clinicians, particularly for children unable to advocate for themselves. When trust was lost, caregivers escalated concerns to administrators or sought care elsewhere. Caregivers relied

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TABLE 4. Navigating Racism and Discrimination in Health Care

Strategy	Definition	Examples
Advocating	Caregivers assertively expressing needs and concerns, sharing information, and refusing procedures or medications to protect the child's best interests	• "I just discovered that when I stand my ground… and I'm able to state my case, um, clearly, and like, with authority as a parent and stuff… they try to engage with me more, um, positively. And … they like sorta took me more seriously." (Caregiver 12, Caregiver of a CMC aged 7 years) • "I'm just more direct… if I think it's something I'm like, "Can you check him for pneumonia? Can you do this particular thing?" Which is frustrating because sometimes I don't know exactly what I'm supposed to be asking for. but making it clear that I'm not just gonna like, passively get dismissed into something." (Caregiver 22, Caregiver of a CMC aged 3 years)
Following instincts	Caregivers sensing when something was wrong and persistently advocating to ensure appropriate care	• "I ask a lot of questions…if it doesn't feel right in my gut, I just ain't gonna let it go." (Caregiver 6, Caregiver of a CMC aged 13 years) • "So many things get swept under the rug because the parent just let it go. But—I feel like most parents have like that instinct… Like, most of the time if you feeling like 'Hey, something not right with my kid,' advocate, like push and fight for your kid… you are their voice." (Caregiver 31, Caregiver of a CMC aged 7 years)
Being informed	Caregivers actively researching, asking questions, and consulting others to better understand conditions, treatments, and systems	• "I try to be very informed. So, people get a sense that I know what I'm talking about. A lot of times, they ask me if I'm a nurse or I'm a doctor or I work in the health care field because I'm very informed about what's going on with him." (Caregiver 20, Caregiver of a CMC aged 5 years) • "I just feel like I'm always guiding them. And so, communicating with my doctors, I know I have to come with factual evidence. I feel like I have to convince them to do what I think needs to happen. I have to look up, investigate, research, come up with what I want to ask." (Caregiver 18, Caregiver of a CMC aged 13 years)
Documenting	Caregivers documenting interactions through notes or recordings to ensure accuracy and accountability	• "I document everything… I feel like if I just go in with like scrambling dates in my head, they're not gonna take me serious… So, I write everything down." (Caregiver 7, Caregiver of a CMC aged 3 years) • "I bring my notepad so I can write things down… Because it's like all the doctors against you. I try to stay on top of things as much as possible. I try to get everything in writing." (Caregiver 18, Caregiver of a CMC aged 13 years)
Managing perceptions: verbal communication	Caregivers intentionally managing their tone, language, and boundary-setting to advocate effectively for their child	• "I try to like make sure that like I'm… like not coming off like in the defensive tone, and I'm making sure that I'm not raising my voice. I… just make sure that I'm wording things correctly." (Caregiver 31, Caregiver of a CMC aged 7 years) • "Being a Black woman in the medical field—you have to say what you mean and mean what you say and put your foot down to let them know—you're no better than me. What you know I can go read or I am already as educated as you are." (Caregiver 10, Caregiver of a CMC aged 12 years)
Managing perceptions: body language	Caregivers consciously managing body language and facial expressions to promote more positive interactions with clinicians	• "If you're sitting, I'm sitting… If we're standing, we're standing… I've learned over time that makes a big difference." (Caregiver 28, Caregiver of a CMC aged 10 years) • "A lot of times—as Black women—we will speak with hands, you know, gestures. And it'll throw people off because they're not used to that…so you have to learn to not react so quickly because of what you're hearing." (Caregiver 10, Caregiver of a CMC aged 12 years)
Managing perceptions: appearance	Caregivers managing appearance (eg, clothing, hair, and grooming) to present themselves and their CMC in ways they felt would help ensure their child received optimal care	• "I would bring an extra change of clothes to before or after school [to] doctor's appointments just to make sure that they look a certain way… making sure to bring books instead of devices so that it would be clear that these are intelligent children." (Caregiver 2, Caregiver of a CMC aged 10 years) • "I notice when my children are dressed a certain way, the treatment is better. I notice when, um, they look like they just threw something on, we're dismissed a lot easier." (Caregiver 2, Caregiver of a CMC aged 10 years)
Holding back	Caregivers limiting or adjusting communication with clinicians, or choosing to ignore or not engage at all, to manage interactions and protect child from stress	• "Well, once I feel like a health care worker or a doctor is really not into what I'm saying or really there for my daughter, I tend to shut down and I give 1-word responses." (Caregiver 6, Caregiver of a CMC aged 13 years) • "The last thing that I wanna do is be perceived as combative or like the angry Black woman stereotype. And I'm not angry, I'm just frustrated. My frustration is perceived as anger sometimes when I'm advocating for myself or my children." (Caregiver 31, Caregiver of a CMC aged 7 years)
Protecting	Caregivers taking physical actions to protect the child and family within health care setting (eg, staying present, monitoring closely, creating physical barriers, or removing the child from harmful or stressful situations)	• "So, I just try to make sure that someone that he knows, someone that I trust is always around and with him when he is seeking any type of medical care if I can't be there." (Caregiver 3, Caregiver of a CMC aged 17 years) • "When communicating with doctors, I observe the doctor more than I be looking at my child because I want to make sure that my child in good hands." (Caregiver 13, Caregiver of a CMC aged 3 years)

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TABLE 4. Navigating Racism and Discrimination in Health Care (Continued)

Strategy	Definition	Examples
Selecting providers	Caregivers changing staff, clinicians, or institutions after suboptimal care, selectively choosing clinicians based on characteristics, or delaying care when trust is low	• "I let them know upfront. 'My child's been misdiagnosed. And I would not stand for it again. So, are you capable of dealing with a child with special needs?' And—if they pause, if the secretary act funny, then you're not for us… You're not gonna waste my time." (Caregiver 24, Caregiver of a CMC aged 13 years) • "I'm very hesitant… I don't trust doctors. And, depending on how they come and approach me in the room, I'll ask for somebody else." (Caregiver 31, Caregiver of a CMC aged 7 years)
Self-care	Caregivers using self-care and coping strategies to manage stress from caregiving	• "So, it took me to say, 'Okay, I'm gonna go into therapy.' And [my husband] actually went into therapy as well. So, we are both working on like the things that we've seen and watched our daughter go through… It's helpful for our marriage." (Caregiver 7, Caregiver of a CMC aged 3 years) • "I think [experiences of discrimination] just influenced me to just honestly pray… and just hope my kids are healthy, so I don't have to fool with the health care system." (Caregiver 23, Caregiver of a CMC aged 1 year)

Abbreviation: CMC, child with medical complexity.

on prayer, affinity groups, family, friends, and therapy for support.

Consequences of Racism and Discrimination

Distrust

Overall, caregivers expressed a deep distrust of the health care system. As one caregiver shared: "[Experiences of racism and discrimination] made me more hesitant to go to the doctor... I don't trust that they have my best interest at hand" (Caregiver 31).

Caregiver Strain

Caregivers described weariness from constant advocacy and "fighting all the time." Caregivers did not want to be adversarial but felt forced into that role to secure equitable care for their child. Caregivers emphasized that caregiving is demanding, and racism and discrimination add to this burden. Caregivers linked the emotional toll of fighting to be heard and constant advocacy to adverse impacts on their own health, including anxiety, depression, and weight loss. Notably, some caregivers hesitated to seek mental health support for fear of CPS involvement. One caregiver who did seek help was reported.

Delayed Diagnosis and Acute Care Use

The theme of delayed diagnosis was common. Caregivers partly attributed this to their CMC's rare medical conditions, but also to repeated dismissal by clinicians. Several caregivers described repeated dismissal of their concerns leading to multiple ED or outpatient encounters before their child's underlying medical issue was diagnosed and treated. Caregivers also described instances of poor communication within medical teams and between teams and caregivers (eg, delayed responses to concerns) that contributed to ED visits. Additionally, perceived experiences of discrimination led some caregivers to avoid seeking care for their CMC unless absolutely necessary.

Positive Interactions

Although most caregivers described experiences of racism, some did not. Several caregivers described positive experiences with clinicians who advocated for them, partnered with them, validated their concerns, proactively connected them to resources, and were knowledgeable about CMC. These experiences were enhanced by clear information about their child's condition and timely responses to caregivers' questions.

DISCUSSION

Caregivers of CMC face numerous challenges including navigating fragmented health care systems and overcoming delays in diagnosis and treatment due to dismissal and limited clinician knowledge about rare conditions.[1,30,31] Our findings extend the current literature by illustrating that, for Black caregivers of CMC, caregiving demands may be further exacerbated by racism and discrimination.

Studies have demonstrated that Black patients experience lower-quality care and poorer communication compared with non-Hispanic white patients.[7–12] Previous work among Black adults with chronic illnesses described frequent discrimination and racism in health care, operating through dismissal, stereotyping, retaliation, and insurance bias.[7] Similarly, nearly 60% of caregivers of CMC have reported discrimination in health care settings, with experiences of discrimination associated with worse caregiver mental health.[32]

Experiences of discrimination can result in distrust and substantial consequences including avoidance of health care, delayed diagnosis, and treatment nonadherence.[33,34] Importantly, previous experiences of discrimination influence how caregivers engage in subsequent health care encounters.[26,35] CMC experience frequent, longitudinal interactions with health care systems. Thus, the cumulative effects of discrimination over time may be particularly harmful in this population.

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The responsibility of addressing disparities in care should not fall on caregivers. Clinicians should reflect on their implicit biases, recognize caregivers' expertise, and engage them as equal partners in decision-making.[36] Listening to and responding to concerns with empathy and respect may strengthen communication and rebuild trust among families who have previously experienced inequitable care.[37]

At the health system level, antibias training and communication coaching may help address the interpersonal discrimination contributing to disparities.[38–41] However, health care organizations must implement sustained efforts to address structural racism and discrimination. Strategies include strengthening mechanisms to report and respond to discrimination, promoting workforce diversity, and implementing equity-focused accountability policies such as tracking differences in health outcomes across populations and incentivizing equitable outcomes.[38–41]

Our study has several limitations. Although our sample reflected a range of educational backgrounds and household incomes, caregiver ethnicity was not collected, all participants were biological parents, and our sample included only 2 male caregivers. Also, although caregivers described experiences across multiple US states, participants resided in only 2 southeastern states. Intersecting identities, including gender, ethnicity, geography, and caregiver role, can shape caregivers' health care experiences. Therefore, our findings may not capture the full diversity of experiences among Black caregivers of CMC.

Furthermore, retrospective accounts and voluntary participation may have introduced recall and self-selection bias. Our analytic team's identities and biases may have also influenced interpretation of findings, although we used multiple strategies to mitigate this (Table 1). Nonetheless, strengths of our study included member-checked results and collaboration with caregivers and family advocacy organizations from study conception to dissemination.

CONCLUSIONS

Our findings reveal that experiences of racism and discrimination in health care shape how Black caregivers of CMC communicate with clinicians and navigate health care. These experiences contribute to distrust, caregiver strain, and perceived negative child health outcomes. To improve care, we must create health care environments where all caregivers feel equitably treated, heard, and respected.

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ABBREVIATIONS

CMC: child with medical complexity
CPS: child protective services
CRTPHP: Critical Race Theory Public Health Praxis
CYSHCN: children and youth with special health care needs
ED: emergency department

MJ White conceptualized and designed the study, coordinated all aspects of the study, conducted interviews, analyzed interviews, contributed to interpretation of findings, drafted, reviewed, and revised study materials, and critically reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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