Patients' Perspectives on Race and the Use of Race-Based Algorithms in Clinical Decision-Making: a Qualitative Study



Insa M. Schmidt, MD, MPH¹, Merav Shohet, PhD², Mariana Serrano, MPH³, Pranav Yadati, BS¹, Hanni Menn-Josephy, MD¹, Titilayo Ilori, MD¹, Nwamaka D. Eneanya, MD, MPH^{4,5}, Emily C. Cleveland Manchanda, MD, MPH⁶, and Sushrut S. Waikar, MD, MPH¹

¹Section of Nephrology, Boston University Chobanian & Avedisian School of Medicine and Boston Medical Center, Evans Biomedical Research Center, 5th Floor, 650 Albany Street, Boston, MA, USA; ²Department of Anthropology, Boston University College of Arts and Sciences, Boston, MA, USA; ³UMass Memorial Health's Office for Diversity, Equity, Inclusion and Belonging, Boston, MA, USA; ⁴Division of Renal-Electrolyte and Hypertension, Perelman School of Medicine, University of Pennsylvania, Philadelphia, PA, USA; ⁵Global Medical Office Fresenius Medical Care, Waltham, MA, USA; ⁶Department of Emergency Medicine, Boston University Chobanian & Avedisian School of Medicine and Boston Medical Center, Boston, MA, USA.

BACKGROUND: Clinical algorithms that incorporate race as a modifying factor to guide clinical decision-making have recently been criticized for propagating racial bias in medicine. Equations used to calculate lung or kidney function are examples of clinical algorithms that have different diagnostic parameters depending on an individual's race. While these clinical measures have multiple implications for clinical care, patients' awareness of and their perspectives on the application of such algorithms are unknown.

OBJECTIVE: To examine patients' perspectives on race and the use of race-based algorithms in clinical decision-making.

DESIGN: Qualitative study using semi-structured interviews.

PARTICIPANTS: Twenty-three adult patients recruited at a safety-net hospital in Boston, MA.

APPROACH: Interviews were analyzed using thematic content analysis and modified grounded theory.

KEY RESULTS: Among the 23 study participants, 11 were women and 15 self-identified as Black or African American. Three categories of themes emerged: The first theme described definitions and the individual meanings participants ascribed to the term race. The second theme described perspectives on the role and consideration of race in clinical decision-making. Most study participants were unaware that race has been used as a modifying factor in clinical equations and rejected the incorporation of race in these equations. The third theme related to exposure to and experience of racism in healthcare settings. Experiences described by non-White participants ranged from microaggressions to overt acts of racism, including perceived racist encounters with healthcare providers. In addition, patients alluded to a deep mistrust in the healthcare system as a major barrier to equitable care.

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Received July 7, 2022 Accepted December 30, 2022 Published online February 22, 2023 **CONCLUSIONS:** Our findings suggest that most patients are unaware of how race has been used to make risk assessments and guide clinical care. Further research on patients' perspectives is needed to inform the development of anti-racist policies and regulatory agendas as we move forward to combat systemic racism in medicine.

KEY WORDS: race; race-based algorithms; race-based eGFR; racism; kidney disease; qualitative research; patient perspective.

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INTRODUCTION

Many clinical algorithms currently in use across medical specialties incorporate information about a patient's race, which is a social construct,^{1–3} to guide clinical decision-making and to provide individualized risk assessments. Pulmonary function tests,⁴ risk scores for heart failure and cardiovascular disease assessment,^{5–7} and, until recently, the estimated glomerular filtration rate (eGFR)^{2,3} are examples of clinical equations that have different diagnostic parameters depending on an individual's race. The validity and longstanding effects of using race-based equations, however, have been questioned and criticized for perpetuating racism in clinical medicine.^{2,3,8} Several studies have shown that the inclusion of race as a variable in clinical equations can reify the debunked idea of race as biologically based and potentially exacerbate existing health disparities.^{2,3,8–12}

In nephrology, the recent re-evaluation of the eGFR equation has provided an important first step toward achieving more equitable care for patients with kidney disease.^{13,14} Recognizing that the use of race to estimate kidney function is an important concern, the joint task force of the National Kidney Foundation and the American Society of Nephrology recently recommended the nationwide implementation of the new race-agnostic 2021 CKD-EPI eGFR equation.^{13–15} Yet, significant additional efforts are needed to address and redress the harmful effects of race-based medicine and to continue to overcome the racial biases embedded in clinical algorithms, medical practice, and care. One strategy to advance equity in medical research and practice is to integrate patients' perspectives and acknowledge their insights into the various ways in which racist practices and racism have contributed to health inequities. While the use of race-based algorithms has been discussed across academic institutions and in transdisciplinary contexts, patients' awareness of and their perspectives on the application of such algorithms are not wellunderstood.

In this study, we sought to elicit patients' perspectives on the use of race and race-based "adjustments" in clinical medicine, hypothesizing that patients' awareness of how "race" has been used to make risk assessments and guide clinical care is limited. This work could inform new policies and regulatory agendas as we move forward to advance health equity by developing a more socially conscious and just approach to the use of race in healthcare and scientific research.

METHODS

Study Design, Setting, and Participant Selection

Using a qualitative descriptive study design, we conducted semistructured interviews to explore patients' perspectives on race and the use of race-based algorithms. We recruited patients > 18 years of age who were proficient in English and who received care through clinics at Boston Medical Center (BMC). In this safetynet hospital, approximately 60% of the patient population are people of color, and 70% of patients recruited for this study relied on Medicaid/Medicare. Study participants were approached in person or by phone, and each participant was interviewed separately. All study participants received a 25 gift card as compensation for their time. The study was approved by the BMC Institutional Review Board (#40720).

Data Collection

The interview guide (Supplemental Box 1) was informed by the authors' previous work and literature reviews.^{8,16–18} The first set of questions was designed to develop a broader understanding of participants' definitions of "race," which laid the foundation for a more detailed exploration of patients' perspectives on how and if race should play a role in clinical care. All interviews were conducted by a non-physician research assistant (M.S., MPH) who received formal instruction in qualitative research methodology and self-identifies as non-White. The research assistant had no relationship with the participants before the interviews. Interviews were conducted between August 2021 and February 2022 via phone, following verbal consent, and were audiotaped and transcribed verbatim. Using open-ended questions, participants were asked to reflect on their own definitions of race, their personal views on the use of race for clinical decision-making, and whether race should be considered by clinicians when making treatment decisions or recommendations. Participants were encouraged to further elaborate on responses and encouraged them to narrate their own personal experiences wherever possible. Results were discussed and evaluated in research team meetings throughout the interview collection process. Recruitment and analysis continued until thematic saturation in the main themes was achieved.¹⁹ Interviews lasted between 12 and 42 min. Demographic characteristics were collected to provide descriptive information about participants, including their self-reported age, ethnicity/race, sex/gender, education, employment, and health insurance status.

Analysis

Interview transcripts were entered into NVivo version 12 1.6.1 (QSR International) and analyzed using thematic content analysis and modified grounded theory. We used line-by-line coding to inductively identify initial concepts and develop a preliminary codebook. Codes for themes were decided by consensus after independent analysis of 6 transcripts and applied iteratively to subsequent interviews (I.M.S., Mariana S., and P.Y.). We resolved disagreements through iterative discussions until consensus was reached to ensure that findings represented the full range and depth of the data. While saturation was reached on the main constructs, we identified a few contradictory cases which contributed valuable depth to the study. The diverse background of the authors (social science and medical anthropology, public health, and clinical medicine) allowed data to be interpreted from diverse perspectives. We adhered to the consolidated criteria for reporting qualitative research (COREQ) (Supplemental Table 1). 20

RESULTS

The baseline characteristics of the 23 patients who participated in semi-structured interviews are shown in Table 1 and Supplemental Table 2. Participants' mean age (SD) was 58 (\pm 15) years; 48% were women. Sixty-five percent self-identified as Black, 35% as White, and 9% as also Latinx. We identified three main themes: (1) definitions and meanings participants ascribe to the term "race"; (2) perspectives on the role and consideration of race in clinical decision-making and patients' awareness of its use in clinical algorithms; and (3) exposure to and experiences of racism in healthcare settings. Respective subthemes are described below, and illustrative quotations are shown in Table 2.

Definitions and Meanings of Race

Defining Race. Almost all study participants defined race as a bodily characteristic that is determined by one's skin color. Six patients reported that race is also a sociocultural characteristic with potential genetic underpinnings, and an important measure of self-identification. As one patient explained, "It's

Age, years	
Mean ± SD	57.6 ± 15.2
Sex, n (%)	
Women	11 (47.8)
Men	12 (52.2)
Self-identified racial/ethnic identity, n (%)	
Black or African American	15 (65.2)
White	8 (34.8)
Latino/a/x, Hispanic, or Spanish origin, n (%)	
Not of Hispanic, Latino/a/x, or Spanish origin	21 (91.3)
Hispanic, Latino/a/x, or Spanish origin	2 (8.7)
Highest grade/level of formal education, n (%)	
High school graduate	9 (39.1)
Some college	5 (21.7)
College graduate	4 (17.4)
Post-graduate degree (MA, PhD, MD, DO, etc.)	4 (17.4)
Less than high school graduate	1 (4.3)
Employment status, n (%)	
Retired	9 (39.1)
Employed full time	5 (21.7)
Employed part time	4 (17.4)
Not employed	3 (13.0)
Disabled	2 (8.7)
Homemaker	0 (0)
Primary health insurance, n (%)	
Medicaid/Medicare	16 (69.6)
Private health insurance (through employer or self-pay)	7 (30.4)
Other/none	0 (0)

a bunch of things. It's genetic background, cultural background, it's how people self-identify and want to be identified" #15.

Meanings of Race. For study participants who self-identified as non-White, the term "race" often related to segregation and division they experienced in the past, including their experiences of racism and police brutality. As one participant put it, "Race to me means you got to know how to carry yourself. If the police pulls up on you, it's all over" #6. Another patient said, "When I look at race I see disparities, differences, which is not fair overall" #11. Yet, some participants also associated race with pride, as one participant asserted, "[My race], I am proud of it" #8. Study participants who self-identified as White more often claimed not to ascribe a particular meaning to race or denied its significance. One patient elaborated, "Race doesn't mean anything to me. A human is just a human. I don't look at Black and White like that" #5. Another patient noted, "I try not to talk about race. To me, it's more about trying to be the best person you can" #13.

Body Function and Race. Most participants believed that race has no influence on body and organ function: "Everyone is human [...] I don't think someone's race affects how their organs would work" #2. A few patients noted that although organ function should not differ by race, the body is affected by the many harms that society inflicts on racialized people: "I bleed red like anybody else [...]. But the heart feels the pain of racism and favoritism" #9. Another patient noted, "there are certain aspects of physiology that have changed [...], you know, not tied directly to the color of a person's skin or

anything like that but because of separation of people for an extended period of time you're going to see different genetic mutations in groups of people' #7.

Race in Clinical Care, Algorithms, and Decision-Making

Considerations of Race for Treatment Recommendations. Most patients who self-identified as non-White stated that race has influenced the care they received in healthcare settings and believed that healthcare professionals currently consider a patient's race when making treatment decisions. One patient commented, "I do think they consider race when it comes to certain options for Black people and certain options for White people. I feel like they feel like maybe we don't have the health insurance to either cover some of the options that they could offer us, or they feel like, we've seen this so much before in this community [...] and the patient just didn't do their part. I think that if I wasn't such an advocate for myself, that I would just get brushed under the radar" #23. Another patient noted, "They talk down to you. I think the medical field came a long way from what it used to be, but they are still hesitant when it comes to a Black person. They're not doing everything they possibly could do, they're not doing that" #6.

Conversely, all participants who self-identified as White believed that their race has had no influence on the care they received ("I don't think that in the course of my care anyone has ever considered that" #2). Another patient said, "Sometimes it's hard for me to see whether I am getting special treatment or not. I certainly don't think I've been mistreated because of who I am. [...] but I may be very ignorant to other people's situation. So certainly, economically, I've experienced things, but because of race, I really haven't felt anything one way or the other" #1.

Most patients believed that race should not be considered when making treatment recommendations ("I think everyone should be treated equally" #20). A few patients noted that the consideration of race, if not used to stigmatize individuals, could potentially help to develop more culturally sensitive and personalized care: "Providers maybe should have some type of sensitivity training [related to] racial diversity or sexual orientation, because when you go to see a provider, you want to feel comfortable. [...] Growing up, I always had a Caucasian nurse practitioner. Now, I definitely do feel a lot better when I can relate to the provider, whether they are female or Black" #18.

Awareness of and Perspectives on the Use of Race in Clinical Algorithms. Most participants were unaware that race has been used as a modifying factor in clinical equations including the calculation of kidney or lung function. Nevertheless, three patients reported to have seen their laboratory reports, stating different eGFR values by race ("I have seen the different GFR based on a number if you're African American and non-African American, and I never understood why that made a difference. [...] I don't know, why does race play a part in me? [...] that's how it's listed on

Table 2 Themes and Subthemes with Descriptive Quotes		
Magnings and definitions of race		
Defining race	"It's the color of your skin." #8	
	"I guess I would define it by color." #3	
	"Race I would define in three ways – the color of a person's skin, their background, and how they	
	were brought up." #22	
	"It is how you identify yourself and your background and any demographics that are given to	
	you." #18	
	"Race is a label in a sense, man has defined races." #4	
Meanings of race	"I define Black as being treated differently." #6	
-	"Race is a hate thing. It means everybody just can't get along together." #10	
	"There is no race []. We are the same – only one race, which is called the human race." #19	
	"It has no meaning to me." #23	
Body function and race / effects on the human	"I consider you have the same liver that I have. I consider you have the same makeup of heart. I	
body	am not talking about healthy or non-healthy, but I consider you having the same organ and heart	
	I do and every human being." #4	
	"No, [race has no effect on organ function] because I think we are all equal." #21	
	"I would assume not, people are very much the same, it's how they are brought up." #22	
	In the sense that some problems that occur are genetically determined but it's dangerous to make	
	assumptions, in general, about individuals based on appearance. #15	
	differences the place you ware here the activity at "#10	
Page in aligned are algorithms and decision making	differences, the place you were born, the food you eat. #19	
Kace in clinical care, algorithms, and decision-making		
recommendations	the treatment I received Many years back high blood pressure was first diagnosed as "Black	
recommendations	disease" [] and people associate diabetes with Black people When I go to a physician	
	they're surprised that I don't have high blood sugar." #4	
	"If they are a good doctor, they should look at everybody the same, as a human, not their race." #21	
	"I don't think [race has been considered], but I would say that is probably because I am racially,	
	culturally considered White, whatever that actually means." #15	
	"It should be a part of how you receive your treatment. For example, the doctor I have seen	
	before, she wouldn't consider my culture. In every culture, they eat differently, we use different	
	ingredients. So, I think they should be aware of how to speak to different races because our	
	backgrounds, our culture, they are different." #8	
	"I want it to be considered, but I don't want it to be a determining factor. I don't want people to	
	ask me things only because I'm Black and they assume I can't afford something." #18	
Awareness of and perspectives on the use of race	"This comes as a surprise to me. I would not have been aware of it." $#2$	
in clinical algorithms	"No, [I didn't know this]. Well, I don't think race should play a factor in it, but it does though." #9	
	I think that's sad. That makes me think about people that need a new kidney []. #12	
	some [1] I don't think like this calculating and eventhing. I don't think it should be like that	
	same. [] I don't unit the unit calculating and everything, I don't think it should be like that because I don't see a difference fly recal $\frac{\gamma}{48}$	
	"I don't think they should use past information from other patients based on their race to treat	
	more patients," #23	
	"My concern with that is the automatic decision making. Doctors use demographics and	
	nationalities to form baseline or general ideas, but I do think that they do need to be vetted, at	
	least to some extent, before a decision is made." #7	
Experience of discrimination or unequal treatment in	the healthcare system	
Experienced racism	"They talk down to you. You know, it's something, I guess, that's something that you're going to	
•	have to get used to." #6	
	"[The provider] put me in the category as 'Black people got more problems with the kidney	
	function,' and I had to stop her right there and tell her don't say that because I don't know who	
	has worse kidney function and I don't think it's the color" #21	
	"Ill give you a perfect example. If a White person comes in and a Black person comes in and they	
	have the same medical issue and they need the same medical attention, they re going to cater to	
	that White person better than they cater to that Black person. If you think I'm bullshitting, all you	
Mistrust of the health same sustain	got to do is to go to the nospital and see now they handle stuff. #b	
Mistrust of the nearthcare system	there is a large like some medicing the three medication. And i ve noticed	
	that, it's always like the same medication that they put minorities on, [] it's Armodipine. []	
	It's even with pain interfaction and nutrition and things on a White person. But they just feal like	
	"Oh well you know these Black people they're always gonna have high blood pressure" I	
	feel like they not us in a certain category. I think it's a preference of medication over	
	therapy." #23	
	"The team I'm working with right now, I think it is a good team because they don't hold back.	
	[] Mainly, I'm working with a Black team, and they take really good care of my treatment. I	
	think me being Black in past days, how would they have handled that? [] I honestly think	
	they would have sent me away, because, you know, the medical field 15 to 20 years ago was a	
	lot different than what it is today." #6	

the results page: African American and non-African American. So, like Black people and everybody else" #18). Nearly all participants also believed that race should not be included as a modifying factor in clinical equations.

Experiences of Discrimination or Unequal Treatment in the Healthcare System

Experienced Racism. Several study participants who selfidentified as non-White reported having encountered racial discrimination in healthcare settings. One patient said, "Some nurses might down you because of your race, or [say that] more Black people have this than White, and it is untrue" #21. Patients also reported barriers to receiving care: "[Black people] are gonna be treated differently. They'll be sitting in the waiting rooms way too long" #6. Reflecting on the diagnostic process for a dermatological condition, one patient noted, "It's less known what those autoimmune conditions will look like on Black skin [...] so it took, I think, longer to diagnose than it would have if I was a White patient." Referring to medical books and journals, he continued, "Doctors are trained on looking at a condition on white skin. When they manifest or appear differently on Black skin, they're not as quick to identify it as what it is because it looks foreign to them based on what their education has been" #7.

Mistrust of the Healthcare System. Participants who identified as non-White also alluded to a general mistrust of the healthcare system among people in the Black community. A main contributor, in addition to experiences of racism and discrimination, was the fear of experimentation: "I've worked in the medical field, and I know that a lot of these doctors, they push medication on patients because of pharma and things like that. And I feel like they use a lot of these experimental drugs on Black people because they put it to them like, 'Oh, well, this is what your insurance can afford'" #23.

DISCUSSION

The effects of systemic and structural racism infiltrate almost all aspects of American society, including the healthcare system. Racist practices permeate clinical medicine in multiple ways such as through explicit and implicit provider biases, through racial stereotyping of diseases, or as implemented in clinical equations and algorithmic tools.²¹

Advocating for a patient-focused approach to developing anti-racist policies in clinical medicine and healthcare, we conducted this study to report patients' perspectives on race and the use of race-based algorithms in clinical decisionmaking. We found different patterns regarding individual definitions and meanings of race, differential awareness of and perspectives on the consideration of race in clinical algorithms and decision-making, and patients' exposure to and experiences of racial discrimination in healthcare settings. These patterns help explain a deep mistrust in the healthcare system and why systemic, institutional racism remains a major barrier to equitable care.

Our findings of diverging definitions and meanings of race among individuals are consistent with those of previous studies in which participants reported a wide range of possible meanings, encompassing physical traits, ancestry, cultural similarity, ethnicity, and social category.^{1,22} The absence of a single, shared definition or meaning of race may reflect individuals' lived experience of intersectional

racial identity formation²² and the important role of internalized racism and its connection to health and well-being.^{23,24} Associations between internalized racism (i.e., the acceptance of negative stereotypes by the stigmatized group about their own race)²⁵ and anxiety, depressive symptoms, and psychological distress, all of which contribute to overall worse health outcomes, have been well documented.^{23,24,26,27}

Most participants in this study were unaware that race has been used as a modifying factor in clinical equations such as the calculation of kidney or lung function and stated that race should not be included in these equations. Several studies have shown that racially discriminatory algorithms can exacerbate existing health inequities.^{2,3,8–}

¹² The "race correction factor" used to calculate pulmonary function, for example, reduces the likelihood that Black patients receive disability support for lung diseases.¹² Similarly, equations currently in use to estimate cardiovascular disease risk provide substantially different risk assessments in Black versus White patients with otherwise identical risk factors.⁷ The finding from our study of patients' unawareness of how race has been incorporated into clinical algorithms highlights the lack of transparency on the use of data on racial categorization in clinical encounters. It also suggests the need for open and sensitive patient-provider communication on these issues to build trust and to reduce barriers to more equitable care.

Patients from historically marginalized and minoritized groups face racism in the healthcare system in multiple ways. The personal experiences participants described in this study ranged from microaggressions (e.g., as one patient noted, being talked down to by healthcare providers) to overt acts of racism, including racist encounters in the healthcare system. Prior studies have consistently shown that experiences of racism are associated with adverse health outcomes and contribute to the disproportionately high mortality rates seen in marginalized and minoritized populations.23,24,28-32 Several people of color who participated in this study expressed awareness that their health is affected by racial inequities, linking disease causation to socio-political and economic structures.³³ One participant also noted how racial bias can shape diagnostics and teaching in a discipline like dermatology where curricular materials center Whiteness and thereby perpetuate racism and racist ideologies by failing to teach trainees how to diagnose diseases on Black skin.³⁴ In contrast, few White participants acknowledged racial differences in treatment. These findings are in line with prior research suggesting that levels of awareness, understanding, and comfort in recognizing and verbalizing processes of racialization differ between White people and people of color.^{22,35} Further research on patients' perspectives is needed to help develop an anti-racist approach and inform the development of policies and regulatory agendas to eliminate systemic racism from medicine.36

LIMITATIONS

Our study has several limitations that warrant consideration. We interviewed English-speaking patients from a single safety-net hospital in Boston, MA. Thus, it is possible that some themes may not have been captured as patients' perspectives and experiences may vary in different healthcare settings, in other socioeconomic brackets, or as related to different educational and cultural backgrounds, and in other regions of the country. Furthermore, it is possible that social desirability bias may have affected our results, as some participants may have censored negative views or experiences which may also have resulted in differing interview lengths. We tried to alleviate this effect by assuring them that the interviewer had no role in clinical care. Lastly, the social identities of the analysis team and conduct of the study in an emotionally charged sociopolitical environment when race-consciousness was heightened in the wake of the COVID-19 pandemic inevitably shaped our interpretation of the data collected and may limit our ability to fully understand and interpret patients' perspectives.

CONCLUSION

Challenging racism's deleterious effects on scientific research and the healthcare system requires a multi-level, anti-racist approach. This encompasses policy and organizational interventions that integrate racialized patients' voices and experiences in the development and design of future research and guidelines, as well as educational and structural reform. Findings from our study underscore the need to center the voices of historically marginalized and minoritized patients when designing research aimed at addressing racism in medicine.

Corresponding Author: Insa M. Schmidt, MD, MPH; Section of Nephrology, Boston University Chobanian & Avedisian School of Medicine and Boston Medical Center, Evans Biomedical Research Center, 5th Floor, 650 Albany Street, Boston, MA 02118, USA (e-mail: ischmidt@bu.edu).

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Declarations:

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