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Black and African American Adults' Perspectives on Discrimination and Unfair Judgment in Health Care

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Study after study confirm that the health care system treats people unequally and patients' care and outcomes vary markedly by race (AHRQ 2020; National Research Council 2004). Though studies of racial equity often focus on disparities in health care access and outcomes, fewer studies examine discrimination in patients' day-to-day interactions with the health care system and the similarities and differences in patients' perceptions, stories, and encounters (Kressin, Raymond, and Manze 2008; Shavers et al. 2012). The COVID-19 pandemic has prompted greater attention to racial inequity in the health care system and both its complex contributing factors, including structural and interpersonal racism, and its consequences for patient health (Chowkwanyun and Reed 2020; Ogendegbe 2020; Shah, Sachdeva, and Dodiuk-Gad 2020).¹

Black and African American people, Indigenous people, and other people of color have endured disproportionately higher rates of COVID-19 cases and deaths during the pandemic.² Thus, examining and addressing questions about differential health care treatment takes on heightened relevance and urgency. So, too, does understanding broader public health consequences. Research draws a connection between providers' differential treatment and discrimination toward patients and patients' distrust in medicine and medical science (Dean et al. 2017; Kennedy, Mathis, and Woods 2007; Suite et al. 2007). As such, how might experiencing past or current discrimination and unfair judgment when seeking health care affect a person's trust in public health messages and guidance during the pandemic, including trust in the vaccines considered the best solution to end COVID-19's dangerous effects (Latkin et al. 2021; Spalluto et al. 2020)?

This brief is part of a body of work exploring perceptions of discriminatory experiences in health care and other settings (Gonzalez, Kenney, et al. 2021; Gonzalez, Skopec, et al. 2021; Pratt and Hahn 2021; Skopec, Gonzalez, and Kenney 2021). Here we present findings from follow-up interviews with 39 Black and African American* nonelderly adults ages 18 to 64 who participated in the Urban Institute’s September 2020 Coronavirus Tracking Survey. In the survey, Black and African American adults reported discrimination or unfair judgment by a health care provider or their staff in the last 12 months at a share three times higher than that for white adults and two times higher than that for Hispanic/Latinx adults (Gonzalez, Skopec, et al. 2021). Because the survey did not probe deeply into these experiences, we designed our follow-up interviews to explore accounts of discrimination and unfair judgment and assess their consequences. Interviews took place between December 2020 and February 2021. We find the following:

- The sample of adults commonly experienced unfair judgment by a doctor, health care provider, or their staff or knew someone who had.
 - » Among the 39 people we interviewed, 22 reported personally experiencing discrimination or unfair judgment when seeking health care at some point in their lives.
 - » Among the 17 people with no such personal experience, nearly half knew a family member or friend who had had such experiences.
- Perceived discrimination and unfair judgment were rarely overt, and many people we interviewed could not discern whether their mistreatment was because of their race specifically or because of a combination of factors, including income, gender, health conditions, and disability.
- Some people were more hesitant than others to label an experience as discrimination without clearer proof or evidence, yet they described encounters that health care research defines as likely discrimination.
- Delayed treatment and critical misdiagnoses were notable negative consequences of perceived discrimination or unfair judgment by doctors, health care providers, or their staff.
- Though most people planned to get a COVID-19 vaccine when it became available to them, most were hesitant about the decision. Those who had experienced perceived discrimination or unfair judgment were more hesitant about the vaccines than those who had not had such experiences.

* In this brief, we use “Black and African American” in recognition that some view “African American” as narrowly representing the histories of some but not all people of African descent in the US (e.g., more recent Black immigrants from Africa, Europe, the Caribbean, and other places). We also recognize that some people prefer one term over the other. Further, in these interviews, people referred to themselves as Black, as African American, or as both. Additionally, the authors have capitalized Black to denote the unique Black experience as one characteristic of a diverse group of people, ethnicities, and cultures. The authors have not capitalized “white,” a term and label for a range of historically grouped ethnicities used to delineate a contrast with people of color. See Margaret Simms, “Say African American or Black, but First Acknowledge the Persistence of Structural Racism.,” *Urban Wire* (blog), Urban Institute, February 8, 2018, <https://www.urban.org/urban-wire/say-african-american-or-black-first-acknowledge-persistence-structural-racism>.

Background

In the following sections, we provide more context and information on the terms and ideas in this report. We also explore what research says about discrimination and unfair judgment in health care settings and discuss how these experiences are measured, including how people think about the terms “discrimination and “unfair judgment,” specifically.

Discrimination in the Health Care System

Racial discrimination is “(1) differential treatment on the basis of race that disadvantages a racial group and (2) treatment on the basis of inadequately justified factors other than race that disadvantages a racial group (differential effect)” (National Research Council 2004). Research distinguishes between interpersonal and institutional racism and discrimination (Shavers et al. 2012; Williams et al. 2019); institutional discrimination includes organizational policies, practices, and social norms that effectively disadvantage or harm members of a stigmatized group, whereas interpersonal discrimination often manifests as targeted, unfavorable behavior toward members of a stigmatized group.

Because interpersonal discrimination occurs between individuals, people may have a hard time discerning if they have in fact been discriminated against (Shavers et al. 2012). Despite these challenges, years of research have identified patterns, features, and consequences of interpersonal discrimination (Jones et al. 2016). Studies frequently find Black and African American people, Indigenous people, and other people of color are more likely than white people to report discrimination in health care. This includes being subjected to stereotyping (e.g., assumed to not have insurance or to be uneducated); being assumed to be unable to afford certain treatment options and then being provided lower-quality ones; receiving improper diagnoses and dismissive, disrespectful treatment; and receiving less satisfactory care (Grady and Edgar 2001; Pascoe and Smart Richman 2009; Stepanikova and Oates 2017). Research shows that such experiences have physiological and psychological effects and take discernible tolls on people’s physical, mental, and emotional health (Richman, Pascoe, and Lattanner 2018; Williams et al. 2019).

In addition to examining interpersonal discrimination in health care from the perspective of the person perceiving the discrimination, several studies examine interpersonal discrimination and implicit bias among doctors and other health care providers. Several demonstrate an association between providers with stronger implicit anti-Black biases and poorer communication with patients (Maina et al. 2018) and less positive attitudes toward people of color (Hall et al. 2015).

Discrimination is also associated with other health consequences and costs, including avoiding or delaying seeking care, being misdiagnosed, or receiving inappropriate treatment (Bleich et al. 2019; Casagrande et al. 2007; Geiger 2003; Virnig et al. 2009). Some studies have shown that in addition to human costs in life years lost, these consequences can also cost the US billions of dollars annually in excess medical spending (Chin 2016; Engelgau et al. 2019; LaVeist, Gaskin, and Richard 2011; Turner 2018; Turner et al. 2020).

Measuring Racial Discrimination in Health Care

Researchers have developed tools to measure discrimination in everyday encounters through interview questions and scales that quantify experiences such as being treated less courteously, provided poorer service than people of another race, or presumed to be violent, less smart, and dishonest—characteristic anti-Black racist stereotypes (Shavers et al. 2012; Williams et al. 1997).

Most research examining discrimination in health care uses general language to capture the different ways patients may experience it, from smaller microaggressions and poor bedside manner to overt discriminatory language and practices (Kressin, Raymond, and Manze 2008). Researchers studying discrimination based on race or ethnicity in health care sometimes refer to such experiences as “unfair judgment,” treating the term as synonymous with terms like bias, discrimination, and overall unfair treatment (Blanchard and Lurie 2004). We found no research examining how study respondents define unfair judgment or whether their perceptions and interpretations of the term match researchers’ assumptions that unfair judgment is the same as discrimination (Kressin, Raymond, and Manze 2008; Shavers et al. 2012). We use both ‘discrimination’ and ‘unfair judgment’ here, and we later investigate what both terms mean to the people we spoke with. A metaanalysis of surveys and scales measuring interpersonal discrimination and other studies highlight the need to understand how patients define and react to their experiences and how, in turn, their health care outcomes are affected (Gonzalez, Skopec, et al. 2021; Kressin, Raymond, and Manze 2008; Shavers et al. 2012).

Research Approach

For this study, we sought to understand patients’ experiences with doctors and other health care providers and the consequences of those interactions. We also focused on the ways people who perceive they have been discriminated against or unfairly judged navigate health decisions and the potential costs of these negative experiences for both individuals and the health care system. We spoke directly to Black and African American adults given their disproportionate reports of discrimination and unfair judgment relative to other groups in the September 2020 Coronavirus Tracking Survey (Gonzalez, Skopec, et al. 2021). We focused on the following questions:

- How does one sample of Black and African American adults experience and view discrimination and unfair judgment by health care providers? What are examples from their own lives and from people they know?
- Are discrimination and unfair judgment the same or different?
- How does experiencing discrimination and/or unfair judgment affect how some people may view and use the health care system?
- How likely are people to get a COVID-19 vaccine when it becomes available to them? Are people who have experienced discrimination or unfair judgement any more hesitant?

Our primary goal was to identify common themes in how patients experience and handle these discriminatory encounters. Our secondary goal was to explore how people interpret discrimination versus unfair judgment. Do the terms capture the same or different types of treatment? Whereas the Coronavirus Tracking Survey asked about discrimination or unfair judgment (i.e., whether the respondent had experienced either one), our follow-up interviews explored each concept separately. We distinguished between the two to assess if some respondents see them as different and to better understand what we and other researchers may miss when we use and analyze these terms interchangeably (Gonzalez, Skopec, et al. 2021; Kressin, Raymond, and Manze 2008; Lillie-Blanton et al. 2000; Shavers et al. 2012).

We hypothesized that some people may perceive the term discrimination as more severe and harmful, requiring greater proof or evidence. A person holding that view may hesitate to call something discrimination but may more freely call the same experience unfair judgment. People also may more readily pinpoint being judged unfairly, because they can recognize and distinguish their actual motives and characteristics from what a provider may wrongly judge to be their motives and characteristics. We care about this distinction because if we find people are describing similar experiences but labelling them differently, we may undercount the prevalence of interpersonal discrimination in the health care system in larger-scale studies asking only if someone felt discriminated against. Similarly, if the concepts differ, some studies may overcount discrimination that might in truth be something conceptually different than discrimination.

Who We Interviewed

We conducted semistructured telephone interviews with 39 Black and African American adults who had previously participated in the September 2020 Coronavirus Tracking Survey. Interviews were 25 minutes long and took place between December 2020 and February 2021. We asked participants to comment on their perceptions of the fairness of the health care system, their experiences with discrimination and unfair judgment while seeking health care, and their thoughts on the COVID-19 vaccines.

For our study, we selected people who reported in September 2020 that a doctor, other health care provider, or their staff had judged them unfairly or discriminated against them in the last 12 months based on their race, ethnicity, gender, gender identity, sexual orientation, health condition, or disability. We also selected people who did not report these experiences to get comparative insights. We used purposive sampling and prioritized recruiting Black and African American people who are women, have low family incomes (below 250 percent of the federal poverty level), and reported delaying care, not getting care, or not following a provider's recommendations because of the treatment they received. We prioritized women and those with low incomes because each was more likely than others in the Coronavirus Tracking Survey to have reported experiencing discrimination or unfair judgment by a doctor or other health care provider (Gonzalez, Skopec, et al. 2021). We also prioritized respondents who reported delaying care, not getting care, or not following a doctor's

recommendations to ensure we spoke with respondents who could provide insights into how experiences of discrimination and unfair judgment affect health.

Our final interview sample included 39 people (24 women and 15 men). Of them, 12 had reported discrimination and unfair judgment from a health care provider (whether related to race or another factor) in the past year, 18 had not reported discrimination or unfair judgment, and 9 had not reported discrimination or unfair judgement but felt the health care system has treated them with disrespect.³ Approximately two-thirds of the sample had reported having a chronic health condition,⁴ compared with less than half of all 720 nonelderly Black and African American adults who had participated in the survey. Nearly half of the people we interviewed were from the South, and a quarter were from the Midwest. Approximately two-thirds of the sample had incomes below 250 percent of the federal poverty level.

As noted, we were interested in experiences of discrimination and unfair judgment regardless of when they occurred (i.e., not just within the past 12 months, as reflected in the Coronavirus Tracking Survey). We therefore wanted to identify people in the survey who may have ever had such an encounter, even if they had not seen a doctor or other health care provider in the past 12 months. Given the pandemic, more people forwent, delayed, or were unable to seek care during much of 2020 (Gonzalez, Karpman, et al. 2021; Mehrotra et al. 2020).⁵ And, as research shows, people may also have delayed care because of previous experiences of unfair judgment or discrimination (Hostetter and Klein 2018; Skopec, Gonzalez, and Kenney 2021; Taylor 2019; Williams and Cooper 2019). For these reasons, we asked everyone we interviewed if they had ever experienced discrimination by a health care provider. We also asked anyone who had not experienced discrimination or unfair judgment to describe their interactions with doctors and other health care providers and their staff to compare perceived discriminatory and nondiscriminatory experiences.

How We Analyzed the Interviews

We interviewed each person individually and took detailed notes and audio recordings of conversations with participants' permission. To analyze the interviews, we systematically reviewed the notes and recordings to transcribe select verbatim responses and categorized participants' answers using a thematic analytical framework mirroring the questions in our semistructured interview guide. We coded and summarized dominant themes using a qualitative software program, NVivo 12, noting commonalities and differences in experiences and opinions. We illuminate key themes, frequent responses, and illustrative examples with select relevant quotations below. Our qualitative interviews provide rich, nuanced information unavailable in the large-sample tracking survey. However, the 39 voices representing 39 different experiences and perspectives far from capture or represent the experiences of all nonelderly Black and African American adults and their views on and encounters with doctors and other health care providers and their staff.

What We Learned

Most people participating in the follow-up interviews felt the health care system is unfair and does not treat people equally.

When we asked whether the health care system treats everyone equally, most of the 39 people we interviewed said it does not. Many people cited race and ethnicity as the primary reasons for unequal treatment in health care. People also attributed disparate treatment to a person's income (whereby people with low incomes are treated less fairly), to being uninsured, or to not having private health insurance coverage. Some said reasons for unfair treatment were multidimensional, based on both race and ethnicity and intersecting factors like socioeconomic background, gender, or health insurance coverage type. Specifically, one person pointed out that the health care system minimizes women's and people of color's health concerns:

“Not as a whole, [but] it seems like a lot of times a lot of mostly people of color and women are treated as we are overblowing the situation. If we feel like there is something wrong or something like that, for the most part, a lot of the times we are patted on the head and told to calm down no matter how serious we think it is.”

A few participants expressed, either explicitly or implicitly, that Black and African American people and other people of color systematically receive unequal treatment in health care. One person provided an example directly tied to race: hysterectomies being recommended at higher rates for Black and African American women and Latina women than for white women. However, most examples of worse treatment related to systemic factors that contribute to Black and African American people and other people of color disproportionately being uninsured, not having private insurance, or having low incomes. Some people noted that they or others had been turned away at a provider's office because of their health insurance coverage type or income. Conversely, some commented that people with private coverage are able to get appointments quickly. Drawing a connection between health insurance and race, one person explained:

“Well, being African American, if you don't have proper insurance, you are not treated as well as someone who has employee insurance through a job. You don't get the same treatment or, if you're low income, don't get the quality care that you deserve. But if you have good insurance, you can get the care that you need.”

Though many of the 39 people we spoke with felt the health care system is unfair overall, nearly two-thirds did not feel their provider's race mattered. For many, the primary criterion when selecting a provider was medical competency. Consistent with another study (Greene and Ramos 2021), several participants explained a competent doctor is one who has appropriate medical training, is honest, communicates well with and listens to patients, and resolves patients' issues (e.g., prescribes the right medication, provides accurate medical advice).

Among the roughly one-third of people we interviewed who preferred providers who share their same race, the primary reason was cultural competency; many felt that Black and African American

providers give them more empathetic care, understand their cultural norms, and generally understand them better as patients.

Despite seeing the system as unfair, several people said they had not experienced discrimination or unfair judgment by health care providers or their staff personally. However, nearly half of these participants knew someone who had.

Among the 27 people who had not reported experiencing discrimination or unfair judgment by a health care provider in the past year in the September 2020 survey, more than one-third (10 people) recounted such an experience at some point in their lives. In total, 17 of 39 indicated they had never personally experienced discrimination or unfair judgment. Far from refuting discrimination happens, several felt they avoid such experiences because they take preemptive steps, such as searching for the best provider for their needs and establishing a relationship with their provider. “What I do is I develop relationships so they know me as a person,” one person said. Several felt the providers they see are generally kind and care about their patients.

Many who never experienced discrimination or unfair judgment stated they have been with their providers for at least 3 years, including some who had seen their providers for more than 20 years. In most cases, people spoke of their primary care physicians, though two spoke about their dermatologists, one their dentist, and another about treatment they received while seeking chronic care services at a hospital.

A few people elaborated that though they generally did not feel personally discriminated against or judged unfairly, they were uncertain about some experiences. Two people we spoke with reasoned they could not claim a situation was discrimination because they did not know the offending individual’s intentions (e.g., perhaps the provider had a busy day). Another did not feel they’d experienced discrimination but added that if they had received differential treatment because of their race, they just may not have realized it. The same person said that any potential discrimination a provider may contemplate (e.g., based on their false assumptions about the participant’s education or capacity) is often dispelled once the provider and participant start speaking, because the participant is well educated. And one person noted that because they could not pinpoint the reason behind a provider’s actions that they did not like, they could not claim it was racial discrimination.

Even though several people in the sample had not experienced discrimination or unfair judgment themselves, nearly half of them knew a family member, friend, or acquaintance who had, suggesting these experiences are common for many Black and African American adults. We note, though, that a couple people questioned if they could believe their friends’ or family members’ accounts; in one case, the person we spoke with shared that their friend tended to be judgmental, and in another, the respondent’s relative may have been unhappy because the appointment did not go how they wanted.

Despite not reporting personal experiences of discrimination or unfair judgment, these adults help shape definitions of discrimination and unfair judgment specific to our interview sample. They used descriptors similar to those in common survey measures of discrimination to describe experiencing the opposite or absence of discrimination during their encounters with doctors and other health care

providers and their staff. In effect, these adults reinforce what discrimination entails by describing in similar terms what it is not. For example, questions in the Everyday Discrimination Scale identify discriminatory treatment as less courteous, less respectful, and involving poorer service than that provided to other people (Williams et al. 1997).⁶ In contrast, most of the people we spoke with who did not experience discriminatory or unfair treatment characterized providers as being courteous and welcoming, building and establishing rapport, and showing they care about and respect patients' opinions, needs, questions, and requests. One person explained that their provider "really cares about their patients and love[s] what they do." Others stated their providers take time to meet with them during their appointments and treat them as they would any other patient. We caution that a person who is courteous and listens could still be engaging in discriminatory behavior, just as a person who is less courteous and less respectful might not be. Still, the people in our study described what being discriminated against or judged unfairly entails in ways that align with the research on such treatment.

Those who had experienced discrimination or unfair judgment by health care providers and staff tended to share similar accounts.

We asked people who had experienced discrimination or unfair judgment by a doctor or other health care provider to tell us about their interactions, just as we asked those who had not had such experiences. Among people who had experienced discrimination or unfair judgment, many reported similar accounts. The specific stories and their potential severity differed (e.g., failing to recognize kidney failure versus being treated coldly at the reception desk). However, as described in more detail below, the stories similarly identified when discriminatory treatment happens (e.g., when entering health care settings and during interactions with doctors and other providers) and what effects it has (e.g., missed diagnoses, misdiagnoses, and denied treatment, especially related to pain medication).

When entering a hospital, clinic, or other provider's office, some participants described experiences such as providers refusing service outright in one case, prioritizing paperwork and signatures before treating a patient who needed immediate help, or having different procedures for different people. One person described facing differential treatment, saying, "They will treat other patients, like Caucasians, before registration but will wait until after registration to check on me. So it's just [an] observation of the different ways that they treated me compared to others."

In some cases, providers did not believe people's reasons for seeking care or that the patient had private insurance. In one account, a receptionist did not look up a person's insurance because the receptionist eyed the patient's Blue Cross Blue Shield insurance card and incorrectly assumed it was Medicaid. Another person described going to the emergency room, where staff assumed the person we interviewed was homeless based on their appearance, which the person in our study said was affected by weight and hair loss from cancer. Not believing the participant's concerns and thinking they instead wanted food, staff members gave this same person a sandwich. Then, "[my] heart started acting up, and they found out I was telling the truth," shared the person we interviewed. And others described waiting longer for care than other patients and being greeted coldly whereas white patients receive a more friendly welcome.

Several people discussed direct interactions with doctors and other health care providers that felt discriminatory or based on the provider making an unfair judgment. Several told us about short visits and getting minimal attention and few questions from providers. “The amount of time they spend with you, the advice they offer, is slip shot,” one person said, “like you don’t matter, like in and out.”

Another common occurrence was having providers who had dismissed or belittled patients’ symptoms, concerns, or preferences. One person described an encounter with a provider from several years prior: “He was condescending...totally disregarding what my symptoms were and actually telling me, ‘That’s just a little this, and that doesn’t really matter,’ when I know the pain I was feeling and what I was going through, and the purpose of coming to him was to address that issue.” The participant concluded saying they felt the provider refused to address their issues.

In addition to discriminatory initial interactions and conversations with doctors and other providers and their staff, some people described unfavorable medical treatment resulting from encounters that felt discriminatory or based on unfair judgment. People most frequently described challenges receiving pain medication in examples ranging from having a severe fall and head injury, to having a hysterectomy, to giving birth. One person described such an encounter, saying, “Their attitudes toward me...just like, their questions, you know, asking me if I took anything already...I don’t know, just not really believing what I’m saying...and a lot of questions.” Another person recalled:

“They [the doctors at the hospital] didn’t want to give me pain medication for it, as if I was some type of dope addict. It kind of made me think it was maybe a racial issue, them not wanting to give me pain medication, because people abuse it too much, so when you need it you can’t get it...That is one discrimination, I feel like, that is unfair to people to color.”

Others described not getting sufficient medication. One woman we interviewed had run out of cancer medication and was unable to get it from the doctor standing in for her regular doctor, who was away on leave. What stood out to the woman, who was certain the reason was racial, was the stand-in doctor’s look: “She looked like she was afraid to death to touch me.” Another participant shared the following:

“There’s a bias among health care that Black men have a higher tolerance for pain, so that if you are given pain medication, it’s quite often not therapeutically enough compared to a comparable patient, a comparable level of pain...A white person will have the most comforting treatment as far as dosing; they [providers] will minimize myself or the Black woman.”

In a few interactions, patients’ dismissed or disregarded symptoms resulted in delayed or missed diagnoses. We heard about a doctor who doubted the symptoms a patient described and reluctantly tested the patient for the flu at the patient’s mother’s insistence. In the end, the patient indeed had the flu. In another example, a patient had kidney failure her initial doctor did not recognize:

“I was going to a doctor, and he basically ignored everything I said about the things that I was telling him about ‘something feels wrong, these things are going wrong,’ that I’m noticing changes in my body, I’m taking on water weight. [The response was], ‘You just need to lose weight, you’re just fat.’ To him everything I said was wrong, I didn’t know what I was talking

about, about myself, and it was my fault. Then I went to a woman doctor who was Black. And with the first labs, she was the first to see that my kidneys were failing.”

Though several people felt race was behind the experiences they had, such experiences were rarely overt. People often described a feeling, or seeing how other patients who were not Black and African American were treated. When asked if the treatment they faced was related to race, one person shared:

“To be honest, growing up in the US, an African American person 99 percent of the time has had something happen because of their race. If you go anywhere for any reason, that something is done repeatedly, and then you don’t question, Do I have to make a change because of this or because of this? And to be honest, I don’t know if it’s race based. At this point, I don’t care if it is race based. I pay almost \$400 a month for health insurance. I refused to be treated off-handedly.”

Another person characterized their experience as “little microaggressions, certain phrases,” adding, “maybe I’m being paranoid, but sometimes things they [providers] say stick with me.” Another person explained it similarly, as “a funny feeling,” saying it “comes to you later...‘Oh, maybe this is why.’” Several acknowledged that they did not have proof that their encounter was discrimination. One participant said, “I have not been openly discriminated [against], but I have felt that better things could’ve been done, and if I was another race, yeah, I probably would’ve had the care that I needed. But I am not able to prove that.”

Many people we spoke with described indignities, rudeness, and a lack of courtesy, caring, listening, and respect. The examples we heard often seemed to have anti-Black racist stereotypes at their core, for example, about Black and African American people’s intelligence and greater proclivity to use drugs or to be poor, dishonest, or people to fear (Moskowitz, Stone, and Childs 2012; Sacks 2018; Taylor et al. 2019). When we asked why people thought they were discriminated against, one person who did not necessarily attribute her treatment to her race replied, “I try not to think about it; I’m still in pain, so why is no one listening to me?” Others were left thinking their treatment was due to their race or other discrimination because they could not otherwise explain it. One person said, “I don’t know. I can’t 100 percent say it’s race related, the only thing I can tell is that when dealing with someone that you know is not being welcoming to you, human nature makes you wonder why. Why is she this way?”

Others were more certain about the origins of their mistreatment. One person shared, “She [the doctor] didn’t think I was intelligent enough to understand my lab results or anything like that. She basically just would refill my prescriptions and not really talk to me about anything that was going on.” Someone else explained, “Sometimes they [white health care providers] think we are overexaggerating when we have symptoms.”

The 39 people we interviewed were nearly evenly divided on whether discrimination differs from unfair judgment.

About half of the people we spoke with believed being judged unfairly and being discriminated against are different. Several who held that view suggested the main difference was that unfair judgment is based on opinion, whereas discrimination is an action. Being judged unfairly meant providers made assumptions about a patient's characteristics or social position, whereas discrimination occurs when a provider acts based on those biases and assumptions. This view suggests discrimination is marked by actions and identifiable results from those actions.

Two people noted that the difference between discrimination and unfair judgment is small and nuanced. Others agreed the terms are different but did not provide a specific definition. Many added that discrimination occurs in multiple areas of life, not just health care. This finding was reflected in our quantitative work as well (Gonzalez, Kenney, et al. 2021).

Six people felt being judged unfairly and being discriminated against were the same, but most of them did not elaborate on their thoughts. Those who did stated both are rooted in making false assumptions about people before knowing them. One person elaborated that these assumptions most often occur because of how a person presents (e.g., their outward appearance, race, or gender) and will lead to the same automatic response from a provider. Any differential treatment owes to the provider's context or environment, characteristics, and beliefs (e.g., stereotypes and biases the provider has grown up hearing or holds). One person shared the following:

“People tend to forejudge an African American based on the color of their skin, because there are so many stereotypes, so many misconceptions about African Americans. I think until someone really takes the time to get to know an individual, they believe what they read, they believe what they see, they believe what they hear, and some people, regardless, even if when they get to know the person, knowing these stereotypes and misconceptions are false, they still hold on to that, because that's kind of what society has told them to do. You're judged simply because of the color of your skin.”

Whether reporting discrimination and unfair judgment as similar or different, most people we interviewed appeared to understand both as related concepts: false knowledge and mistreatment by some doctors and other health care providers and their staff. This understanding also explains why participants' varying accounts had the same essential features, even when people labeled them differently (i.e., as unfair judgment versus discrimination).

We conclude that people will and do see unfair judgment and discrimination differently. Some people are more likely to define such experiences as discrimination, whereas others are less inclined without further evidence. We saw this among both people who reported experiencing unfair judgment or discrimination and a few people who said they had not personally experienced such treatment but then acknowledged encounters that conceivably could have been discriminatory.

Looking across each story and experience, we conclude that encounters that qualify as “differential treatment that disadvantages a racial group” or are based on “inadequately justified

factors,” as indicated in the definition of racial discrimination in National Research Council and coauthors (2004), are likely more prevalent than what many surveys suggest. Such experiences were also more prevalent among the group we interviewed than was reflected by their responses in the initial September 2020 survey.

People reacted differently to perceived discrimination and unfair judgment, but most did not take direct action. Among those who had experienced such mistreatment, the most common consequence was delayed treatment.

We asked the 22 people in our follow-up sample who said they had personally experienced discrimination or unfair judgment if they felt a need to respond at the time, and if so, how. We also asked if being judged unfairly or discriminated against affected what they thought about the medical advice, treatment, or other help they were seeking and if their health was affected in any way.

Most people we spoke with did not take direct action (e.g., making a formal complaint or confronting the person directly) in response to experiencing discrimination or unfair judgment. The two main reasons people did not do so were (1) fearing a complaint would interfere with the service they were receiving (i.e., delay treatment) and (2) feeling submitting a complaint was too difficult. Some noted that some situations are too hard to document, or the complaint process would be too complicated. Others believed the complaint would not lead to any disciplinary actions or changes.

Among people who acted in response to their treatment, the most common actions were (1) finding another provider and (2) submitting a complaint with the provider’s administrative office or supervisor or the person’s own insurance company. Two people noted that family members helped report the discrimination; one said their family member helped them find a new doctor, and the other mentioned their family member helped expedite service delivery. Recent work assessing the consequences of unfair treatment or judgment in health care finds similar patterns (Skopec, Gonzalez, and Kenney 2021).

Among those who described negative effects of mistreatment, most said delayed treatment was the most significant effect. People explained that difficulties scheduling appointments, delays in getting prescribed medication, and/or having to identify a new doctor extended the time it took to address their health concerns. To avoid seeing their dentist again, one person attempted to fix their own teeth when they were broken. The teeth simply deteriorated until the patient was able to find a new dentist. Another person stated they still had not received treatment for their health concern and were currently in pain. Three said they are now hesitant to believe their providers’ advice and often seek second opinions or conduct their own research as an assurance.

Others in our sample who had experienced discrimination or unfair judgment reported the experience did not affect what they thought about the medical advice, treatment, or other help they were seeking. Several stated they continued to follow the medical advice provided to avoid delaying care. One person stated their health issue was not serious, so ignoring their provider’s advice did not affect their health. Other people we interviewed did not provide further clarification.

People who experienced discrimination or unfair judgment tended to be more hesitant to get a COVID-19 vaccine than those who had not had such experiences. However, most still planned to get vaccinated.

Between December 2020 and February 2021, when we conducted our interviews, the US Food and Drug administration issued emergency-use authorization for three vaccines,⁷ but none were widely available to most adults.⁸ We asked everyone how likely they would be to get a vaccine when one becomes available to them.

A little more than half of the 39 people we interviewed were concerned about getting a COVID-19 vaccine; most of them wanted more evidence that it is safe for people over time. Nearly three-quarters of the 22 people who had experienced discrimination or unfair judgment were hesitant, compared with a little less than half of the 17 who had not personally had such experiences. Many stated they would like to see how vaccinated people react over the next few months. Several also feared side effects, believing the vaccines were too new or developed too quickly.

Despite these concerns, nearly two-thirds of participants who had experienced discrimination and were hesitant about a vaccine and more than half of those who had not experienced discrimination but were hesitant about a vaccine said they would likely get vaccinated. Three mentioned wanting approval from their doctors first to ensure the vaccines would be safe for them given their health situations. Two others told us they would be required by their employer to get the vaccine, and one person had already been vaccinated at the time of the interview.

Among those who were reluctant to get a vaccine, three were hesitant because of historical medical racial experimentation and discrimination (e.g., one person mentioned the Tuskegee syphilis experiment⁹). One person said they would not get a vaccine because they have seen family members pass away from COVID-19, and they feared developing the virus from a vaccine.¹⁰

For anyone hesitant to get vaccinated, we asked who they would trust to give them accurate information about the vaccines' safety and efficacy. Despite many people in these interviews feeling the health care system is unfair or that it treats people unequally and several participants having experienced discrimination or unfair judgment, many still named health care providers as a trusted source for vaccine information. This finding is consistent with other work on trusted sources of information on COVID-19 vaccines (Karpman and Zuckerman 2021). Other trusted sources include the Centers for Disease Control and Prevention and Dr. Anthony Fauci, the director of the US National Institutes of Allergy and Infectious Diseases, as well as news, the internet, and family and friends. One person mentioned their employer as a trusted source.

Still, 6 of the 39 people we interviewed maintained that no specific source could change their reluctance to take a COVID-19 vaccine. Though some stated they would never change their opinions, others said seeing people's reaction to the vaccines over time may give them more confidence in the vaccines.

Discussion and Conclusions

We heard varied accounts of perceived discrimination or unfair judgment by a doctor or other health care provider from 39 Black and African American adults ages 64 and younger across the country. Though 12 people reported having had this experience within the past year, another 10 had experienced it at an earlier point in their life, and another 8 had not had such an experience personally but still knew a friend or relative who had.

[A provider treating someone fairly] asks a lot of open-ended questions, not direct, closed questions. [The provider] wants to hear and elicit a response from me to get to know me better as a human being, not just a diagnosis. [The provider] is very personable, meaning, for one, she talks with you, not at you. She...actually asks you how medications are working.

—Interviewee

Perceived discrimination or unfair judgment often involved a health care provider being rude, uncourteous, or dismissive; discounting symptoms; misdiagnosing; and treating patients as unintelligent, not understanding of their own symptoms, or dishonest. Many examples also concerned pain medication that was either not prescribed, difficult to get, or of inadequate dosage. These reports are similar to decades of research describing disparities and discrimination in treatment for pain (Bonham 2001; Drwecki et al. 2011; Grady and Edgar 2001; National Research Council et al. 2004; Tait and Chibnall 2014).¹¹ The stories we heard about discrimination that occurred when entering a health care setting, interacting with doctors and other health care providers, and receiving diagnoses or treatment echoed themes from many other studies (Attanasio and Hardeman 2019; Blanchard and Lurie 2004; Grady and Edgar 2001; Kressin, Raymond, and Manze 2008; Krieger 2014; Lillie-Blanton et al. 2000; Shavers et al. 2012).¹²

Regardless of whether people experienced perceived discrimination or unfair judgment, they generally agreed that appropriate, fair, and nondiscriminatory care should entail courtesy, respect, and listening. They also felt high-quality care and treatment require treating people with dignity and recognizing their humanity, value, and rights. Most people we spoke with did not feel having doctors, health care providers, and other staff who shared their same race was critical. Many asserted that medical competency mattered more, and that competence means delivering humanizing, respectful, empathic, caring, appropriate, and skilled treatment. We recognize and caution, though, that such treatment does not mean discrimination is not happening, just as perceived mistreatment might not always be discrimination.

Another common theme was that perceived discrimination and unfair judgment were rarely overt; many participants could not identify whether their treatment was because of their race, income, gender, health conditions, disability, or a combination of factors. Research should not ignore or minimize the complex intersectionality at work and should instead recognize that asking people to focus on a single dimension of who they are (e.g., race) when discussing interpersonal discrimination or unfair judgment is likely unrealistic. That said, that Black and African American adults were more likely to report discrimination of any kind (even if not attributed to race) than all other groups in the larger September 2020 Coronavirus Tracking Survey indicates race plays a role, even if multifaceted, in perceived differential treatment.

We also learned that whereas some participants felt being discriminated against or being unfairly judged are the same, others felt the terms differ. Still, most people described specific accounts that suggested the general concepts are similar. We conclude that including both terms together in a survey question, as done in the September 2020 Coronavirus Tracking Survey, may protect against some undercounting of perceived discrimination among people who require a higher standard of confirmation to consider something discrimination as opposed to unfair judgment.

As noted, most people felt the health care system is unfair and does not treat everyone equally. Perhaps some foundation or hope for building a better, more just system may be found in the fact that most people still considered their health care providers trusted sources for accurate information about the COVID-19 vaccines. Relatedly, we learned that most people in the study planned to get a vaccine when one became available to them, but many were still concerned about the vaccines' safety at the time (in early 2021, before vaccines were widely available to all adults in the US).

Our more concerning findings relate to the consequences of interpersonal discrimination and unfair judgment. Such consequences for health, specifically, are an area for future research. Most often, people told us about delayed treatment. Delays in care can have serious adverse consequences for patients and their loved ones and potentially, as some research shows, for costs to the health care system. In addition, many participants did not alert anyone to their mistreatment, typically feeling it would not be addressed. Because they are not receiving complaints, however, providers may not realize that some patients are simply leaving to find other providers or delaying treatment in ways that could further harm their health. Also, when providers and their staff are not alerted to the problems they are creating, they do not attempt to get better.

Though more tested solutions and research are needed, many people have proposed promising changes to policies and practices that could reduce Black and African American patients' exposure to discrimination and its consequences in health settings (Bazinsky and Bailit 2019; Brooks-LaSure et al. 2020; Hostetter and Klein 2018; Taylor 2019; Taylor and Weerasinghe 2020; Williams and Cooper 2019). Such strategies include the following:

- Requiring that providers and other health care staff undergo ongoing training so they can recognize and disrupt their implicit, unconscious, and explicit biases. This would include

implementing explicitly antiracist policies at health care practices that require both providers and front-office staff to provide equitable and culturally effective care and services.

- Bolstering existing and establishing new mechanisms to hold providers and their staff members accountable for mistreatment and discrimination in health care. This would include stronger enforcement of civil rights, attaching incentives and penalties to health equity goals, and publicizing data on practices with the greatest inequities in health outcomes.
- Diversifying the backgrounds of health care professionals and their staff to align with the communities they serve. This could be achieved by expanding and targeting scholarships to medical students who are Black and African American, Indigenous, or other people of color and/or from economically and demographically diverse communities. Another helpful policy could be implementing robust mentorship programs to recruit and retain these students in medical education institutions.
- Investing in research that assesses which public and private interventions reduce inequitable health outcomes and funding those interventions.

Notes

- ¹ Janette Dill, Odichinma Akosionu, J'Mag Karbeah, and Carrie Henning-Smith, "Addressing Systemic Racial Inequity in the Health Care Workforce," *Health Affairs Blog*, September 10, 2020, <https://www.healthaffairs.org/doi/10.1377/hblog20200908.133196/full>.
- ² "Risk for COVID-19 Infection, Hospitalization, and Death by Race/Ethnicity," Centers for Disease Control and Prevention, updated May 26, 2021, <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html>.
- ³ We originally intended to recruit 20 interviewees who had reported unfair judgment or discrimination in health care settings but did not reach that target. To identify interviewees who might have had such experiences at other points in their lives, we identified 9 respondents who stated they had not experienced discrimination or unfair judgment in the past 12 months but noted that the health care system treats them with less respect than others or that they do not trust the health care system. We selected these respondents based on their responses to questions assessing trust and respect in the health care system and health care providers from the March/April 2020 Health Reform Monitoring Survey. All respondents to the September 2020 Coronavirus Tracking Survey also participated in the March/April 2020 Health Reform Monitoring Survey.
- ⁴ The September 2020 Coronavirus Tracking Survey asked, "Do you currently have a health condition that has lasted for a year or more or is expected to last for a year or more? This could be a physical health condition (such as arthritis, asthma, cancer, dementia, diabetes, heart disease, high cholesterol, hypertension or stroke), a behavioral health or mental health condition, or a developmental disability."
- ⁵ Cynthia Cox, Krutika Amin, and Rabah Kamal, "How Have Health Spending and Utilization Changed during the Coronavirus Pandemic?," Peterson-KFF Health Systems Tracker, March 22, 2021, <https://www.healthsystemtracker.org/chart-collection/how-have-healthcare-utilization-and-spending-changed-so-far-during-the-coronavirus-pandemic/#item-start>.
- ⁶ The five examples in the nine-item Everyday Discrimination Scale include, "You are treated with less courtesy than other people are. You are treated with less respect than other people are. You receive poorer service than other people at restaurants and stores. People act like they think you are not smart. People act as if they are afraid of you" (Williams et al. 1997). The scale uses six response categories ranging from "never" to "almost every day."

- ⁷ The three available were the Pfizer-BioNTech, Moderna, and Janssen (Johnson and Johnson) vaccines. See “Pfizer-BioNTech COVID-19 Vaccine,” US Food and Drug Administration, May 26, 2021, <https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/pfizer-biontech-covid-19-vaccine#additional>; “Moderna COVID-19 Vaccine,” US Food and Drug Administration, April 1, 2021, <https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/moderna-covid-19-vaccine>; and “Janssen COVID-19 Vaccine,” US Food and Drug Administration, June 10, 2021, <https://www.fda.gov/emergency-preparedness-and-response/coronavirus-disease-2019-covid-19/janssen-covid-19-vaccine>.
- ⁸ “A Timeline of COVID-19 Vaccine Developments in 2021,” *American Journal of Managed Care*, June 3, 2021, <https://www.ajmc.com/view/a-timeline-of-covid-19-vaccine-developments-in-2021>.
- ⁹ “The Tuskegee Timeline,” Centers for Disease Control and Prevention, last reviewed April 22, 2021, <https://cdc.gov/tuskegee/timeline.htm>.
- ¹⁰ Doctors, immunologists, and other health officials have deemed this as erroneous information and indicate the vaccines do not contain the virus. See “Myths and Facts about COVID-19 Vaccines,” Centers for Disease Control and Prevention, updated June 3, 2021, <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/facts.html>.
- ¹¹ Maggie Fox, “Black Kids Get Less Pain Medication Than White Kids in ER,” ABC News, September 14, 2015, <https://www.nbcnews.com/health/kids-health/black-kids-get-less-pain-medication-white-kids-er-n427056>.
- ¹² Nina Martin and Renee Montagne, “Black Mothers Keep Dying after Giving Birth. Shalon Irving’s Story Explains Why.,” *All Things Considered*, NPR, December 7, 2017, <https://www.npr.org/2017/12/07/568948782/black-mothers-keep-dying-after-giving-birth-shalon-irvings-story-explains-why>.

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