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## Research and Applications

# Maybe they had a bad day: how LGBTQ and BIPOC patients react to bias in healthcare and struggle to speak out

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### ABSTRACT

**Objective:** People who experience marginalization, including Black, Indigenous, People of Color (BIPOC) and Lesbian, Gay, Bisexual, Transgender, Queer, Plus (ie, all other marginalized genders and sexual orientations) people (LGBTQ+) experience discrimination during healthcare interactions, which negatively impacts patient-provider communication and care. Yet, scarce research examines the lived experience of unfair treatment among patients from marginalized groups to guide patient-centered tools that improve healthcare equity.

**Materials and Methods:** We interviewed 25 BIPOC and/or LGBTQ+ people about their experiences of unfair treatment and discrimination when visiting healthcare providers. Through thematic analysis, we describe participants' immediate reactions and longer-term consequences of those experiences.

**Results:** We identified 4 ways that participants reacted to discrimination in the moment: Fighting, Fleeing, Excusing, and Working Around Bias. Long-term consequences reflect 6 ways they coped: Delaying or Avoiding Care, Changing Healthcare Providers, Self-prescribing, Covering Behaviors, Experiencing Health Complications, and Mistrusting Healthcare Institutions.

**Discussion:** By describing how patients react to experiences of unfair treatment and discrimination, our findings enhance the understanding of health disparities as patients cope and struggle to speak out.

To combat these problems, we identify 3 future directions for informatics interventions that improve provider behavior, support patient advocacy, and address power dynamics in healthcare.

**Conclusions:** BIPOC and LGBTQ+ patients' perspectives on navigating unfair treatment and discrimination in healthcare offers critical insight into their experiences and long-term consequences of those experiences. Understanding the circumstances and consequences of unfair treatment, discrimination, and the impact of bias through this patient-centered lens is crucial to inform informatics technologies that promote health equity.

**Key words:** bias, implicit, sexism, sexual and gender minorities, perceived discrimination, patient harm, interview

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## INTRODUCTION

Substantial research demonstrates disparities in healthcare quality and outcomes for Black, Indigenous, People of Color (BIPOC) and Lesbian, Gay, Bisexual, Transgender, Queer, Plus (ie, other marginalized genders and sexual orientations) people (LGBTQ+).<sup>1–5</sup> Implicit bias contributes to poor care quality and has a detrimental impact on the physical and mental health of BIPOC and LGBTQ+ people.<sup>2–6</sup> For example, Black patients experience worse pain management treatment than White patients<sup>7</sup> and have been stereotyped by some healthcare providers as drug-seeking.<sup>8</sup> Black patients experience worse health outcomes than their White counterparts, even when statistically adjusted for socioeconomic status,<sup>9</sup> feel unheard by healthcare institutions, and experience psychosocial hardships, such as stress and anxiety due to discrimination experienced while seeking healthcare.<sup>6,8</sup>

LGBTQ+ patients experience similar “minority stress”—the stress brought on due to minority status leads to the internalization of that stress, which in turn leads to worse health outcomes.<sup>10</sup> Subsequent injustices include barriers to gender inclusive care,<sup>11</sup> reduced primary care utilization,<sup>12</sup> reduced cancer screening,<sup>13</sup> and healthcare avoidance after experiencing slurs, microaggressions, and harassment.<sup>14</sup> Historical stigmatization shapes the information practices of transgender and nonbinary people<sup>15</sup> and is codified in electronic health records.<sup>16</sup> Providers may hold implicit and explicit prejudices toward gay and lesbian people<sup>17</sup> and may not be up-to-date on LGBTQ+ health needs,<sup>18</sup> which result in inequities in healthcare quality and access.<sup>19</sup>

Providers can hold biases, including implicit attitudes and stereotypes that affect behavior and decision-making<sup>20</sup> and lead to unfair treatment, discrimination, and impact care for groups of people who are marginalized.<sup>21,22</sup> A 2020 national survey of patient-reported experiences found discrimination to be prevalent: 21% of respondents reported experiencing discrimination in US healthcare.<sup>23</sup> Experiences of unfair treatment and discrimination in healthcare interactions among Black and Hispanic/Latino/a/e/x patients have received greater recognition with the COVID-19 pandemic.<sup>24</sup> Given the difficulty of measuring how bias-driven provider behavior harms people from marginalized groups,<sup>2</sup> a deeper understanding of patients’ lived experiences is critical to address bias in healthcare and its harm to patient–provider communication and trust. This understanding can both identify future informatics interventions to reduce such biases<sup>25</sup> and mitigate intervention-generated inequities in healthcare.<sup>26</sup>

In prior work,<sup>27</sup> we interviewed BIPOC and LGBTQ+ patients about their lived experiences of unfair treatment in healthcare and reported 10 broad themes: Transactional care, power inequity, communication casualties, bias-embedded medicine, system-level problems, bigotry in disguise, fight or flight, and the aftermath. In a short abstract, we also reported on intersectionality that surfaced in interviews as a crucial consideration for patient-centered informatics solutions.<sup>28</sup> This article reports in depth on a subset of interview themes regarding the short-term and long-term effects of discrimination. We extend prior work by detailing common ways that people from marginalized groups react to healthcare discrimination and the longer-term consequences they face. The negative impacts of discrimination toward BIPOC<sup>7,11,29</sup> and LGBTQ+<sup>10,12–14,30,31</sup> people are well-documented in healthcare, but informatics solutions to address health inequities are still emerging.<sup>16,25</sup> As Veinot et al discuss,<sup>25</sup> when designing informatics interventions, it is critical to engage people from marginalized communities and shift the focus

upstream from individual behavior at the “micro” level to social, cultural, and environmental factors that impact health and healthcare at the “meso” and “macro” levels.

To inform future upstream interventions, this article contributes a detailed account of reactions and consequences of unfair treatment among BIPOC and LGBTQ+ people—2 groups known to experience marginalization and disparities due to healthcare discrimination.<sup>6,9,14</sup> Although both groups include broad categories of people from diverse backgrounds, their common experiences and understandings from their intersectional identities can enrich knowledge of the patient experience and inform upstream interventions that promote health equity.

## MATERIALS AND METHODS

### Objective and study design

The purpose of this qualitative interview study was to describe how patients experience discrimination in interactions with their healthcare providers. In prior work,<sup>27</sup> we describe a breadth of experiences from interpersonal to structural levels. This article contributes an in-depth description of 2 key themes regarding how patients react and the consequences of those experiences. Our methods are fully described in Ref.<sup>27</sup> Using the orientation of phenomenology, we conducted 1-h semi-structured interviews to collect patient stories about experiencing unfair treatment when interacting with healthcare providers. We analyzed those stories to describe participants’ reactions to unfair treatment associated with their marginalized identities, and longer-term consequences. To characterize the participant sample, we collected demographic data through an online survey. Study procedures were approved by the University of Washington Institutional Review Board. We provide methodological details using the Consolidated criteria for reporting qualitative research (COREQ) checklist<sup>32</sup> in Multimedia [Supplementary Material #1](#).

### Study population and recruitment

To describe the experiences of people from diverse backgrounds who experience healthcare discrimination, we engaged BIPOC and LGBTQ+ individuals. We recruited adults 18 years of age and older who describe themselves as LGBTQ+ and/or BIPOC, speak English, and reside in the United States. We used convenience sampling by posting flyers to our research project’s social media “fan page” (<https://www.facebook.com/unbiased.health>), distributing online flyers through healthcare networks, and snowball sampling through word-of-mouth referrals from previous participants. Interviews took place from June to November 2020. No participant had an established relationship prior to study commencement. Recruitment continued concurrent with qualitative analysis until thematic saturation was reached (see “Data analysis” section).

### Data collection

Before the interview, participants completed an online survey to provide demographics (ie, age, gender, race, ethnicity, education) and responded to the 10-item Day-to-Day Unfair Treatment subscale of the Experience of Discrimination (EOD) scale, a validated self-report measure of discrimination.<sup>33</sup> Participants were interviewed over Zoom by 2 interviewers who were graduate student research assistants with qualitative experience: RC-P, a Latino nonbinary LGBTQ+ person and CA, a Hispanic/Latino cisgender man. Interviewers reviewed survey data before interviews to keep the

participant's background in mind. After introductions, one interviewer acted as lead, asking interview questions, while the second interviewer asked follow-up questions and took notes. The lead interviewer asked participants to describe instances in which they experienced unfair treatment in their interactions with a healthcare provider: "Tell us about a time where you or someone you know had a conversation with a doctor that could have gone better where you felt treated unfairly, not heard, disrespected, or made uncomfortable? What specific things contributed to things not going well?" Interviews were recorded and transcribed immediately. Afterwards, interviewers debriefed and reviewed notes. There were no repeat interviews. Multimedia [Supplementary Material #2](#) provides the online survey and interview guide.

### Data analysis

We summarized survey data with descriptive statistics to characterize the sample. We applied thematic analysis<sup>34</sup> to transcripts to inductively identify emergent themes by iteratively coding the interview data. A team of 4 coders (RC-P, CA, EBa, and DM) reviewed and coded transcripts, referencing notes, and applied and expanded the codebook until reaching consensus (See Multimedia [Supplementary Material #2](#) for codebook). The coders used Atlas.TI v.9 to code 2 transcripts weekly until all transcripts were analyzed, iterating on codes, their definitions, and discussing coding and thematic discrepancies until reaching consensus with no new themes (ie, saturation). Two coders are cisgender women (DM and EBa), one is a cisgender man (CA), and one is non-binary (RC-P). Two coders identify as Hispanic/Latino (CA and RC-P), one as Asian (DM) and one as White (EBa). After the analysis was complete, we shared results with the project's community champions for comment.

## RESULTS

### Participants

Twenty-five participants were recruited from around the United States and completed interviews (P1–P25). Most participants were under 50 years old, non-Hispanic/Latino, and college-educated. Nearly one-quarter of participants described their gender other than cisgender woman or cisgender man and represented racial backgrounds from historically marginalized communities ([Table 1](#)).

On the survey, most participants reported experiencing discrimination in their daily life ([Table 2](#)). When asked for the main reason, the most common response was race or shade of skin color.

### Emergent themes

When prompted to describe times they felt treated unfairly, participants described a range of biased interactions with healthcare providers, ranging from microaggressions and indirect slights to overt displays of discrimination. Participants described a wide variety of healthcare providers and services including emergency medicine, sports medicine, reproductive medicine, psychiatry, and primary care. Thematic analysis identified common reactions to and consequences of those experiences. We report on 2 main themes: (1) *Reactions to unfair treatment*—4 ways participants immediately responded in the moment, and (2) *The aftermath*—6 long-term consequences reflecting how participants coped with those experiences. While we engaged a broad and diverse sample, participants with multiple marginalized identities often focused on only one aspect of their identity during interviews, making adequate comparison be-

**Table 1.** Participant characteristics

|   |           |
|---|-----------|
|   | 25 (100%) |
| <b>Age</b>  |           |
| 18–29   | 15 (60%)  |
| 30–50   | 9 (36%)   |
| 50+   | 1 (4%)    |
| <b>Gender</b> (participants could select more than one)                                       |           |
| Man   | 4 (16%)   |
| Woman   | 17 (68%)  |
| Non-binary  | 5 (20%)   |
| Transgender   | 2 (8%)    |
| Cisgender   | 0 (0%)    |
| Agender   | 0 (0%)    |
| Gender fluid  | 1 (4%)    |
| Prefer not to disclose  | 0 (0%)    |
| <b>Race</b> (participants could select more than one)   |           |
| White   | 5 (20%)   |
| Black or African American   | 8 (32%)   |
| American Indian or Alaska Native  | 3 (12%)   |
| Chinese   | 5 (20%)   |
| Filipino  | 1 (4%)    |
| Asian Indian  | 4 (16%)   |
| Vietnamese  | 0 (0%)    |
| Korean  | 1 (4%)    |
| Japanese  | 0 (0%)    |
| Other Asian   | 1 (4%)    |
| Native Hawaiian   | 0 (0%)    |
| Samoa   | 0 (0%)    |
| Chamorro  | 0 (0%)    |
| Other Pacific Islander  | 0 (0%)    |
| Some other race (fill in): "Middle Eastern," "Latinx," "Mestizo," "Taino"                     | 4 (16%)   |
| Prefer not to disclose  | 0 (0%)    |
| <b>Ethnicity</b>  |           |
| Not of Hispanic, Latino, or Spanish origin  | 18 (72%)  |
| Mexican, Mexican American, Chicano  | 2 (8%)    |
| Puerto Rican  | 1 (4%)    |
| Cuban   | 0 (0%)    |
| Another Hispanic, Latino, or Spanish origin (fill in): "Salvadoran," "Guatemalan," "Filipino" | 3 (12%)   |
| Preferred not to disclose   | 1 (4%)    |
| <b>Education</b>  |           |
| Less than high school   | 1 (4%)    |
| High school graduate  | 1 (4%)    |
| Some college  | 4 (16%)   |
| Bachelor's degree   | 12 (48%)  |
| Graduate/Professional degree  | 7 (28%)   |
| Prefer not to disclose  | 0 (0%)    |
| <b>Which group(s) best describe you?</b>  |           |
| BIPOC   | 11 (44%)  |
| LGBTQ+  | 3 (12%)   |
| BIPOC and LGBTQ   | 10 (40%)  |
| Other group (fill in): "Asian Woman"  | 1 (4%)    |

tween groups difficult. As such, we describe the broader commonalities across experiences of people from these marginalized groups. Our codebook (Multimedia [Supplementary Material #2](#)) provides the distribution of codes mentioned by each group (ie, BIPOC, LGBTQ+, both BIPOC and LGBTQ+).

### Reactions to unfair treatment

The first theme, *Reactions to unfair treatment*, describes participants' immediate responses to unfair treatment when interacting with healthcare providers. We identified 4 ways that participants de-

**Table 2.** Day-to-day unfair treatment subscale of the EOD scale

|   | 25 (100%) |
|---|-----------|
| You have been treated with less courtesy than others                        | 21 (84%)  |
| You have been treated with less respect than other people                   | 21 (84%)  |
| You have received poorer service than other people at restaurants or stores | 24 (96%)  |
| People have acted as if they think you are not smart                        | 22 (88%)  |
| People have acted as if they are afraid of you                              | 14 (56%)  |
| People have acted as if they think you are dishonest                        | 17 (68%)  |
| People have acted as if they're better than you are                         | 24 (96%)  |
| You have been called names or insulted                                      | 20 (80%)  |
| You have been threatened or harassed  | 19 (76%)  |
| You have been followed around in stores                                     | 18 (72%)  |
| What do you think was the main reason for this/these experience(s)?         |           |
| Your ancestry or national origin  | 2 (8%)    |
| Your gender   | 2 (8%)    |
| Your race   | 8 (32%)   |
| Your age  | 1 (4%)    |
| Your religion   | 0 (0%)    |
| Your height or weight   | 1 (4%)    |
| Your shade of skin color  | 3 (12%)   |
| Your sexual orientation   | 0 (0%)    |
| Your education or income level  | 0 (0%)    |
| A physical disability   | 0 (0%)    |
| Other ("combination of many above factors", "I look like a thief")          | 3 (12%)   |
| Did not respond   | 5 (20%)   |

scribed their reactions: *Fighting*, *Fleeing*, *Excusing*, and *Working around bias*.

*Fighting* entails immediate self-advocacy during unfair treatment or discrimination, at the risk of being seen as a "rabble-rouser" (P16). P15 described being condescended to by his providers for seeking Sexually Transmitted Infection (STI) medication:

Specifically, I had a pharmacist who... was just very curt with me and then I had a nurse who said, "If you were my son, I would lecture you on ways that you could be safe." and I responded with, "Well I'm glad I'm not your son." (...) she was standing above me, hands on her hips... literally lecturing me as if she was my mother. (P15: White, Black and Taino LGBTQ+ Puerto Rican man, aged 30–50)

Nearly half of participants (12/25) recounted confronting unfair treatment or discrimination in this way, which was often emotionally taxing, invited backlash, and reflects a skill learned over time. For example, P21 described her ability to self-advocate as being self-taught in opposition to her upbringing:

...It's taken me how many years of my life to be able to speak up against somebody in a position of power because I was taught not to do that. (P21: Non-Hispanic Asian Indian BIPOC woman, aged 30–50)

*Fleeing* entails tolerating unfair treatment or discrimination and passively disengaging from potential conflict. Over half of participants (15/25) described this reaction to unfair treatment. For example, P1 recounted an experience of requesting STI tests when seeing a new primary care provider while his usual primary care provider was on vacation. While his usual provider was aware of his sexual orientation and often ordered such tests, P1 was uncomfortable speaking out for himself to the new provider:

(The provider) actually didn't order any tests. I was just like, "you know, it's OK." ...I told him that I would just basically wait it out and [if] any symptoms came up... I would order a test then, but at the end... he [had not] ordered any tests for me... I didn't really want to be there. And I felt like I was begging for these tests. (P1: Non-Hispanic Chinese BIPOC and LGBTQ+ man, aged 18–29)

*Excusing* entails dismissing the provider's behavior or denying that unfair treatment or a discriminatory transgression has occurred. The most prevalent Reaction to Unfair Treatment, 16/25 participants described *Excusing* unfair treatment from their providers. Whereas 5 of the 11 BIPOC participants mentioned excusing, it was mentioned by all 3 LGBTQ+ participants and by 7 of the 10 participants who are both BIPOC and LGBTQ+. Four participants explained that rather than exhibiting discrimination, maybe the healthcare provider "had a bad day" (P2, P3, P11, P20) and that the provider's unpleasantness was due to stress and the difficulty of healthcare work, rather than bias. For example, P3, told us:

It's like they can overlook things, you know. See, I'm the type that if you do one thing wrong, I always find the good in other people. It's, like, oh, maybe they had a bad day... I always think of excuses for other people first, if I get mistreated. But if they've mistreated me like [with] not just the tone of voice, but like the body language, and if it's more than once or twice, then I get upset. But the beginning, I always say "Everyone has a bad day. You know, nobody's perfect, right?" I always say that for other people, for myself. (P3: non-Hispanic Chinese and Asian woman aged 50+)

*Working around bias* describes other ways participants navigate unfair treatment, discrimination, and bias, enacting subtle ways to encourage providers to reconsider choices that may be influenced by implicit bias. Few participants (3/25) described ways of *Working Around Bias*, but those who did were more often successful in being heard. For example, when P7 was not given pain medication for an athletic injury. He told us that he was advised by a mentor to:

Ask for [the provider] to write down the reason why they're denying it for you... [M]ost of the time they'll give it to you... it's a way of defeating some implicit bias. (P7: non-Hispanic Middle Eastern BIPOC man aged 18–29)

In another example of a workaround, P19 explained that her husband, a white man, would often act as an intermediary between them and the provider, leveraging his privilege to access the care she needed:

...my husband [was] pissed off and bent out of shape. He was the one who basically spoke up for me. He was the one who said, "No, no, no, no, we need to get these tests done." ...The funniest thing is, I told the exact same thing to a doctor, but they don't listen to me. I'm the patient but you're going to listen to my husband? He's not in my body. (P19: non-Hispanic Black or African American and Korean BIPOC woman aged 30–50)

### The aftermath

The second theme, the Aftermath, describes the consequences of experiencing unfair treatment or discrimination in healthcare. We identified 6 responses that reflect how participants coped longer-term: *Delaying or avoiding care*, *Changing healthcare providers*, *Self-prescribing*, *Covering behaviors*, *Experiencing health complications*, and *Mistrusting healthcare institutions*.

*Delaying or avoiding care* describes participants deliberately not seeking future care out of avoidance for further unfair treatment or

discrimination. Nearly half of the participants (12/25) reported using this coping strategy. P11 recounted a dental visit during which her local anesthetic did not take effect while her wisdom teeth were removed. Throughout the procedure, P11 repeatedly attempted to tell her care team that she was in extreme pain, but the care team repeatedly dismissed her. P11 did not seek dental care again until it was life-threatening, years later:

...it was so traumatic that I didn't go to the dentist again for six years. And so I actually went to the dentist again because I had... a previous cavity from my teen years and it had broken... You could you die from a bursting abscess, you know, and so I had to. I had to go to like essentially an emergency situation... I didn't feel heard and the end result was so like, ah, that I was like, "I'm never going to the dentist again unless I absolutely have to." (P11: non-Hispanic Black or African American BIPOC and LGBTQ+ woman aged 18–29)

*Changing healthcare providers* entails participants attempting to find other providers that provide better care and rapport. The majority of participants (16/25) described Changing healthcare providers. This theme was mentioned by 5 BIPOC participants, 1 LGBTQ+ participant, and 9 who are both BIPOC and LGBTQ+. For example, P14 described changing providers multiple times to seek a diagnosis for their chronic pain, only for her to be seen as seeking opiates:

I ended up switching doctors quite a few times, because I was running into barriers. I felt like no one would help me. So I went to a new clinic and I met with a new doctor... I didn't ask for pain medication. I actually don't even tolerate opioids, so that's not a good option for me... I almost felt as if they were suspicious. Like I was doctor shopping when in reality I was just trying to get someone who would actually work with me and give me the next step. (P14: non-Hispanic Black or African American BIPOC and LGBTQ+ woman aged 18–29)

Another participant, P8, an international student not accustomed to the US healthcare system, described seeing a gynecologist for a checkup at her college's health center. During her appointment, P8 described the physician making racial remarks, "not acting professionally," and carrying out the appointment in ways that made P08 uncomfortable:

I didn't really know what was the right thing for doctors to be doing at the time, I didn't say anything. I just assumed that, "Okay, maybe this is like normal procedure." And I think that it was one of those things where, because of the way that I looked and my background and me not being as familiar with a lot of like the Western customs, I felt like they took advantage of the fact that I didn't know much about what was supposed to be normal. (P8: a non-Hispanic Chinese LGBTQ+ and BIPOC woman aged 18–29)

Not only was P8 deeply troubled by this experience, she would only seek female gynecologists thereafter. This physician would later be removed from their position due to severe allegations from other students.

*Self-prescribing* describes instances in which participants sought alternative treatment to the one recommended by the provider. Only 3/25 participants described self-prescribing, using it as a method of last resort. Rather than to continue to pursue treatment and engage in further confrontation, some participants described seeking treatment through other means and taking their health into their own hands when the conversation between patient and provider broke down. For example, P2 told us:

And the only reason that I got better was because I had brought antibiotics from the Philippines and I called a doctor relative...

he told me what to take and, like, how to take it. Probably not the healthiest thing, but I would not have gotten better. (P2: Chinese and Filipino BIPOC woman aged 18–29)

*Covering behaviors* describes ways that participants changed their behavior and appearance to be seen as non-belligerent and untroublesome. One-third of participants (8/25) expressed the need to use covering behaviors when receiving healthcare. In some cases, participants went to great lengths to appear professional, learning and using clinical jargon, and adopting mannerisms and affectations to help clinicians feel more socially comfortable. Participants often did this in the hopes that by acting this way, they would be seen as more credible and trustworthy. For example, P16 described dressing professionally to be heard:

...I'll even wear, because I'm an executive, so I'll... make sure that I'm like suited that day. You know, like head to toe... Let me put on my professional attire. Sadly, it still doesn't work most [of the] time... that's part of the process. I actually have to prepare myself in that way... and be selective about what I choose to wear that day... I want to go in like my leggings. You know, like everybody else. (P16: non-Hispanic, Black or African American, American Indian or Alaska Native BIPOC woman aged 30–50)

*Experiencing health complications* describes poor health outcomes that were worsened or complicated by the experience of discrimination. One-quarter of participants (6/25) recounted times they were not taken seriously, leading to misdiagnosis. P21 described multiple attempts to convince providers to order magnetic resonance imaging (MRI) scans due to grievous leg pain. After multiple misdiagnoses, the source of the pain was discovered on an MRI, but at that point P21's condition had worsened considerably and required expensive surgery:

And I think, actually, if they had listened to me beforehand, I probably wouldn't have been as injured as I ended up... I think that further impeded my body so that I had even more damage. Like, I think the minuscule tears could have been like more severe and the strain on my bones were certainly not something that would have happened if I was treated properly initially... that ended up with me required to have [more] surgery... I had to go back to work. (P21: non-Hispanic Asian Indian BIPOC woman aged 30–50)

*Mistrusting healthcare institutions* describes loss of faith in healthcare providers and institutions. Nearly one-third of participants (9/25) described mistrust as a consequence of unfair treatment, which often led to later action-oriented Aftermath responses, like Delaying or avoiding care, or Changing healthcare providers. As P21 stated after her repeated attempts to be seen for their chronic conditions:

...I think I'm always on guard... I am scared. I kind of have to watch my back... I can't just trust them. (P21: non-Hispanic Asian Indian BIPOC woman aged 30–50)

When asked how unfair treatment impacted them, P8, an international student who felt taken advantage of by their healthcare provider shared:

I definitely was really young, then. And it's been like some time and I've had like time to kind of heal and process. But yeah, it was definitely a bit shocking. And it kind of rubbed me the wrong way about doctors in general... I think it's really important to have these conversations and see how we can... increase awareness... and compassion and make sure that... [doctors]

aren't taking advantage of situations where people feel vulnerable. (P8: non-Hispanic Chinese BIPOC and LGBTQ+ woman aged 18–29)

## DISCUSSION

Understanding patients' lived experiences with discrimination in healthcare is crucial to inform upstream interventions that reduce disparities. We found that people from marginalized groups respond to these experiences by engaging in *Reactions to unfair treatment* (ie, Fighting, Fleeing, Excusing, Working around bias), which are associated with longer-term coping strategies and consequences in *the Aftermath* (ie, Delaying or avoiding care, Changing healthcare providers, Self-prescribing, Covering behaviors, Experiencing health complications, Mistrusting healthcare institutions). This detailed description of how patients react to and cope with discrimination contextualizes the cumulative effects of discrimination known to negatively impact health.<sup>29</sup>

Prior research describes the prevalence of patient-reported experiences of discrimination.<sup>14,23,35</sup> Experiences of discrimination lead to reduced healthcare utilization,<sup>12</sup> care delays,<sup>13,31</sup> and care avoidance<sup>14,31</sup> that negatively impact the health of BIPOC<sup>29</sup> and LGBTQ+ people.<sup>10,30</sup> The mechanisms that contribute to the negative impact of discrimination on health are not fully understood. Our findings corroborate what prior research has only gently touched upon—discrimination is often felt only *after* the initial discriminating event because of the delayed realization of feeling treated unfairly.<sup>36</sup> Patients often must process the complexity of the event to fully realize what took place, which may leave individuals with less energy and resources to engage in healthcare<sup>6,37–39</sup>—a form of minority stress.<sup>10,40</sup> Our findings give further context to the experience of minority stress in healthcare interactions and reasons for lack of continuity of care among people from marginalized groups.<sup>41–43</sup> Beyond patient-centered insights on how discrimination leads to poor healthcare experiences, our findings carry implications for how informatics interventions can help, including tools for providers, for patients, and for addressing power dynamics within the healthcare system.

### Tools for providers

Thoughtfully designed informatics interventions can promote equitable patient experiences by improving provider behavior. For example, training innovations to improve patient-centered communication can play a central role in mitigating bias and discrimination by disrupting the known negative associations between clinician implicit bias and patient satisfaction, trust, and outcomes.<sup>22,44</sup> Reflection, the act of ruminating and learning from one's own behavior, and feedback, external information collected for the sake of improvement, are both fundamental and familiar teaching tools in medicine.<sup>45</sup> Technologies that build on individual feedback and reflection strategies have the potential to reduce incidents that patients experience as discrimination and foster more effective patient-provider interactions. Future research should investigate technological enhancements to implicit bias training tools that provide clinicians with feedback on their individual behavior for reflection, such as real-time feedback on nonverbal communication,<sup>46,47</sup> data-driven dashboards to improve clinical care, and tools for guided reflection.<sup>48</sup> At the meso level, healthcare systems can adopt such tools as one component of a quality improvement program to improve health equity, thus improving

communication skills among providers and patient experiences at the organization level. Other strategies include training clinicians in culturally competent care through interaction with simulated BIPOC and LGBTQ patients.<sup>25,48,49</sup> For example, “MPathic-VR,” improved clinical communication training by enabling medical students to practice challenging conversations with virtual agents outside of real patient care.<sup>50</sup>

### Tools for patients

Tools that support patient advocacy in the face of discrimination offer another opportunity for improvement.<sup>27</sup> Such tools could empower individuals who experience discrimination to *speak out* rather than *excuse*, and foster coping strategies in *The Aftermath*. For example, improvements are needed to create more inclusive technology for patients to report grievances after discriminatory experiences.<sup>51</sup> Beyond micro-level interventions that target individual behavior, there are opportunities for upstream focus on social, political, economic, and physical contexts at meso (ie, structural) and macro (ie, environmental) levels.<sup>25,52</sup> Peer support tools at the meso-level, such as online communities that document experiences of marginalized groups,<sup>53,54</sup> provide an avenue for learning and sharing strategies for coping with discrimination in healthcare. Equitable approaches to community-based collaborative design<sup>55</sup> have the potential to guide the development of meaningful patient-facing discrimination reduction interventions with the experiential knowledge of people from the very historically marginalized communities being served.

### Tools for addressing power dynamics

Health informatics interventions at the macro level are also needed. People from marginalized groups have experienced a long history of systemic discrimination, leading to distrust in healthcare, limited access and adoption of health technologies, and widening of health disparities.<sup>26,29</sup> To close this gap, interventions that account for the socioeconomic, cultural, and political context of healthcare are needed. For example, health equity dashboards can leverage an institution's electronic health record to detect biases in care for marginalized patient populations. Such innovations can leverage informatics resources to expand on existing strategies for Implicit Bias Recognition and Management (IBSM) interventions<sup>49</sup> that target behavior change at the individual clinician and institutional levels. Consider a cultural shift in the design of electronic health records that recognize and represent the marginalized identities of patients<sup>16,56</sup> and offer evidence-based educational resources on caring for and communicating with diverse patients in inclusive and respectful ways.<sup>15</sup>

### Strengths, limitations, and future work

Due to COVID-19 restrictions against in-person research, we recruited through virtual means like social media, skewing our sample to younger people who use social media. Participants were required to use Zoom for interviews which may have resulted in participants with greater comfort and access to technology. We conducted a rigorous qualitative analysis with diverse coders and shared results for comment with our project's community champions, who are individuals from BIPOC and LGBTQ+ groups. Although we engaged a diverse sample of participants from marginalized groups, the sample size is too small to draw conclusions about group differences or intersectionality. Further research should explore whether similar experiences are held by individuals in other groups. Despite

these limitations, our findings capture the personal stories of participants during a time of social awareness and discourse on discrimination following the 2020 Black Lives Matter movement and the disproportionate negative impact of COVID-19 on people of color and other historically marginalized groups. This study provides social and cultural context for unfair treatment in healthcare during a time in which health inequity was, and should continue to be, a much-discussed social issue. Our results capture common lived experiences across a diverse group of people from marginalized populations, and provides a basis for targeted research in the future. A stronger understanding of patient experience with emphasis on patients from marginalized groups, including the role of intersectionality, is essential to creating technologies that can detect and mitigate bias and discrimination in healthcare.

## CONCLUSION

Our findings describe reactions to and consequences of discrimination among BIPOC and LGBTQ+ patients in healthcare. These findings expand prior research by detailing patients' reactions to unfair treatment and discrimination and its consequences, with implications for the design of patient-centered technologies that can address the experiences of patients from marginalized groups and improve healthcare equity. To combat bias-driven unfair treatment and discrimination, future informatics research and interventions should target bias and discrimination not only at the micro level (eg, provider behavior), but upstream at the meso and macro levels through tools that facilitate patient advocacy and address power dynamics in healthcare. In an era where healthcare is driven by data, it is crucial to listen to patients and understand their experiences. Future work should investigate informatics strategies to detect and mitigate bias-driven behavior in healthcare.

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## AUTHOR CONTRIBUTIONS

CA, RC-P, CL, EBe, DM, DV, JS, WP, and ALH made substantial contributions to the conception and design of this work; CA, RC-P, EBe, and DM conducted interviews, coded, and analyzed data; CA drafted the paper and revised it critically for intellectual content with detailed feedback from RC-P, ALH, JS, and WP.

## SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

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## CONFLICT OF INTERESTS STATEMENT

None declared.

## DATA AVAILABILITY

The data underlying this article will be shared on reasonable request to the corresponding author.

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