# Community Perceptions of Health Equity: A Qualitative Study

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## Abstract

**Introduction:** Notable inequities in patient experiences exist in the healthcare system. Communities with a large concentration of blacks and immigrants are often marginalized rather than centralized in the healthcare system. These inequities may fuel distrust and exacerbate adverse outcomes, thereby widening the health gap. Addressing differences in patients' experiences of care is paramount for reducing health inequities.
**Methods:** In this qualitative study, we used a purposive sampling method to recruit 62 participants to conduct 10 FGs (44 participants total) and 18 key informant interviews with stakeholders across Central Brooklyn.
**Results:** The data revealed three primary themes: Trust, Discrimination, and Social Determinants of Health (SDOHs). Each theme comprised subthemes as follows: For Trust, the subthemes included (1) confidence in the healthcare professional, (2) provider empathy, and (3) active participation in healthcare decisions. Regarding Discrimination, the subthemes involved (1) racism and identity, as well as (2) stigma related to diagnosis, disease state, and pain management. Lastly, for Social Determinants of Health, the key subtheme was the acknowledgment by providers that patients encounter competing priorities acting as barriers to care, such as housing instability and food insecurity. For the first theme, participants' interactions with the healthcare system were prompted by a necessity for medical attention, and not by trust. The participants reported that experiences of discrimination resulting from identity and stigma associated with diagnosis, disease state, and pain management amplified the disconnect between the community, the patients, and the healthcare system. This also exacerbated the poor healthcare experiences suffered by many people of color. For SDOHs, the participants identified housing, food security, and other various social factors that may undermine the effectiveness of the healthcare that patients receive.
**Conclusions:** Improvements in the health system, based on feedback from patients of color regarding their unique care experiences, are important initiatives in combating inequities in healthcare.

## Keywords

access to care, community health, health outcomes, patient-centeredness, underserved communities

## Introduction

Patient of color experiences, often associated with the perception of care, measure the totality of interactions that patients have with the health-care system.[1,2] As patient-centered care initiatives gain momentum,[3] it becomes essential to monitor patient of color experiences and satisfaction with the health-care system. While there are government-mandated surveys that are used to carry out this task, most surveys do not address patients' of color experiences of discrimination during care or their trust in their providers, which are important aspects of health-care encounters from the patients' perspective.[3,4] For example, the Consumer

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Assessment of Healthcare Providers and Systems (CAHPS) survey, launched in 2006, assesses patients' perceptions of their care, including communication with nurses and doctors, staff responsiveness, cleanliness, quietness, and the discharge process.[4,5] While these dimensions are crucial, the failure to address explicit experiences of racism, discrimination and trust issues[6-8] represents a major oversight in uncovering the experiences of people of color and potential differences in their care encounters. Disparities in morbidity and mortality are mostly attributable to underlying chronic conditions coupled with a legacy of economic disenfranchisement and disinvestment in marginalized and minoritized communities.[9,10] People of color have long been described as marginalized and minoritized within the health-care system due to racism, mistrust, and gaps in patient–provider communication.[5,11] This characterization refers to the systemic and structural processes that result in the exclusion, discrimination, and limited opportunities experienced by individuals from non-white racial and ethnic backgrounds.[10-12]

In addition to the well-known disparities in morbidity and mortality, there were also notable differences in the process of care and patient experience.[2,4] For instance, the COVID-19 pandemic served to highlight underlying racial and ethnic disparities as well as illuminate differences in patients' experience with care.[13,14] According to the Centers for Disease Control and Prevention, the number of cases, hospitalizations and deaths within African Americans, Hispanics and American Indians were significantly higher than for White adults.[15,16] The North and Central Brooklyn communities, in which 80% of the residents identify as Black or Latino/Hispanics, were among the "hot spots" of the COVID-19 pandemic.[17] Black adults in Brooklyn were twice as likely to require hospitalization for COVID-19 compared with White adults.[15,18] During the pandemic, Blacks were more likely to report delays in receiving testing, in increased emergency room wait-times, and miscommunication during visits.[15,16,19]

These health disparities are inextricably linked to underlying racism—belief that some races are superior or inferior to others, leading to discriminatory practices.[9,20] Racism has been shown to have significant effects on health outcomes, quality of care, and overall health outcomes,[9,21] thereby widening the health gap.[22] Furthermore, research indicates that implicit bias - unconscious attitudes, beliefs, and stereotypes held by individuals about particular groups of people—influences their judgment and actions towards those groups.[21] People of color often experience these implicit biases, resulting in negative patient outcomes and contributing to health disparities.[5,23]

Negative patient experiences may also deter patients from seeking care and have significant implications for future public health responses. Placing greater emphasis on patients of color feedback regarding their health-care experiences is crucial in reducing health inequities. This study aimed to evaluate the experiences of patients of color in Central Brooklyn, allowing community hospitals to identify areas of inequity within their institutions based on consumer feedback. These findings can help institutions implement interventions, such as quality improvement initiatives, to enhance and improve patient care and health outcomes, particularly in areas with existing health inequities.

To tackle health disparities, a partnership was formed between academic institutions, patient advocacy councils, community stakeholders, and healthcare safety net institutions serving Central Brooklyn. Together, they developed the Brooklyn Health Equity Index (BKHI), specifically catered to the needs and experiences of residents in Central and Northeast Brooklyn. The BKHI was launched at the clinical sites within the BKHI, which serve the communities of North and Central Brooklyn. Funded by the NYS Health Foundation, BKHI will inform the design of patient- and system-level health equity metrics for use by institutional leadership and healthcare payers. The BKHI comprises three phases: (1) research and analysis, (2) development of the BKHI prototype, and (3) deployment of the BKHI. This index goes beyond traditional patient experience surveys to uncover experiences of discrimination in healthcare settings. It also measures provider empathy, cultural humility, structural racism, and trust. The One Brooklyn Health System (OBHS) is currently integrating the index into routine patient experience evaluations to guide equity-focused quality improvement efforts. This article reports on the first phase of the BKHI, which involves community-engaged research.

## Methods

Central Brooklyn, known for its large immigrant and Black population, stands out as an outlier in New York City, with a disproportionate burden of poverty, disease, and mortality.[24] Relative to more affluent communities, residents of Northern and Central Brooklyn experience a higher prevalence of cardiovascular disease and cancer.[25] Moreover, life expectancy in these regions is approximately 6 years lower than in more affluent communities.[24-26]

### Research Team

The BKHI project leadership team consists of the faculty of State University of New York Downstate, One Brooklyn Health System, and Arthur Ashe Institute UH (AAIUH). The project was overseen by a community change committee (CCC) comprised of two community stakeholders. The CCC was engaged in all aspects of the research process, including concept and protocol development, outreach, recruitment, data collection, data analysis, dissemination, and evaluation. Including the community in the research protocol allowed

the project to be rapidly processed/formatively evaluated, especially during instrument development.

### Theoretical Framework

This study aimed to utilize patient of color experiences to develop a community-driven, equity-focused metric for change. The health equity implementation framework,[27] guided the integration of patient experiences as the foundation for interventions that identify and address inequities in health-care settings. This framework recognizes multiple determinants or domains operating at the individual, organizational, community, and policy levels, which interact and influence health disparities and equity.[27] Within each domain, cultural factors, such as medical mistrust or biases; patient–provider interactions; and the social context of economies, physical structures, and social and political processes, play a role in health-care equities. By adopting the health equity framework, this study (1) employs qualitative research to understand the perceptions of patients of color toward inequities, (2) designs interventions that respond to their needs, and (3) adapts implementation strategies based on patient experiences.

### Recruitment and Sample

We recruited participants from members of the community, from community-based organizations, and SUNY Downstate and the One Brooklyn Health System. Recruitment took place from October 2021 through January 2022. Following Creswell, we utilized purposive sampling. We initially identified key informants from the BKHI core team, which comprises eleven individuals. These informants were chosen based on their expertise and ability to provide valuable insights into the problem or topic, ensuring diverse perspectives from patients, healthcare trainees and professionals, and community advocates. We then utilized a combination of virtual and in-person venue-based recruitment methods, such as participating in clinics or patient advocacy council Zoom meetings, to leverage our social networks through snowball sampling. Additionally, we collaborated with clinical leadership at the institutions involved in the study to promote it using study flyers and encourage focus group participation from key stakeholders, including medical students and patients. We considered any community member or organization with a political, financial, human, social justice interest or influence on equitable healthcare delivery as a stakeholder. Every participant gave their written or oral consent to participate in the project. A $50 gift card was offered to each focus group participant and key informant as an honorarium for their dedicated time in participating in our focus groups or interviews. This study was approved by the Institutional Review Board of SUNY Downstate Health Sciences University and One Brooklyn Health.

**Table 1.** Demographic Breakdown of Focus Group Participants.

| Focus group | Overall, $N = 44^a$ (%) |
| --- | --- |
| Sex | |
|   Female | 34 (77) |
|   Male | 10 (23) |
| Race/ethnicity | |
|   White | 8 (18) |
|   Black | 35 (80) |
|   Asian | 1 (2) |
| Role | |
|   CAB[b] | 8 (18) |
|   Medical student | 10 (23) |
|   Patient | 26 (59) |

[a]*n* (%), % = *n*/*N*.
[b]Community advisory board.

## Methods

### Data Collection and Demographics

Separate guides were developed in advance for conducting focus groups (FGs) and key informant interviews. The guides were developed based on the following a priori themes: addressing disparities, discrimination in health care, trust/medical mistrust, implicit bias, provider responsiveness, cultural sensitivity, structural competency, social health determinants, and patient safety. Ten FGs ranging from 4 to 8 members were conducted for patients, community patient advocates, and medical students. The average length of the FG session was 90 minutes. All FG interviews were held once, except for one group, which was interviewed twice, based on the group's request to provide additional insights. In addition, we conducted 18 key informant interviews with hospital administrators, health care providers, patients, and community patient advocates. Due to the ongoing pandemic, the FGs and key informant interviews were conducted and recorded through Zoom. To ensure confidentiality, the participants used fictitious names of their choice. The FGs and key informant interviews were held during business hours, in the evenings, and on Saturdays. In total, 62 participants were recruited, aged 21 to 76 years (Tables 1 and 2). As is the case with most phenomenology studies, we determined our sample size based on the principle of data saturation. We stopped collecting data when we were no longer obtaining any new significant information. The FGs and key informant interviews were conducted by the African American project director and the other female African American researcher.

### Data Analysis

Interpretative phenomenological analysis (IPA) was used as the guiding approach to explore the participants' lived

**Table 2.** Demographic Breakdown of Key Informant Participants.

| Key informant characteristic | Overall, N = 18[a] (%) |
|---|---|
| Sex | |
| Female | 13 (72) |
| Male | 5 (28) |
| Race/ethnicity | |
| White | 4 (22) |
| Black | 13 (72) |
| Hispanic/Latino | 1 (6) |
| Role | |
| CBO staff | 7 (39) |
| Hospital staff | 10 (56) |
| Patient | 1 (6) |

[a]n (%), % = n/N.

experiences. The recorded interviews were transcribed by medical students who received stipends for their contributions. In preparation for data analysis, three qualitative researchers read the transcripts several times to build familiarity and begin interpreting the data. The mixed-method data management software known as Dedoose was used to create, update, and revise the codes, most of which were generated from participants' words or phrases. These words or phrases were purposely chosen to retain the voices of the participants and to reflect the lived experiences of the participants, which allowed the researchers to interpret the data from an emic perspective. After the codes were created, connections between emerging themes were discovered and grouped together according to conceptual similarities, and each cluster was attributed a general theme. The three qualitative researchers also participated in intercoder agreement, wherein they analyzed the data, reached a consensus on the codes and emerging themes, and compared them to ensure consistency and concordance. A weekly team meeting consisting of seven members was held to make reflections and observations about the data. The team also focused on the content, initial interpretative comments, and personal reflexivity or biases that might have influenced data interpretation.

As recommended by Maxwell,[28] we assessed trustworthiness of the data through the following: First, the researchers listened to the interview's audio recording, analyzed, and assessed the consistency of the initial analysis. There was broad agreement among researchers regarding the identification of major themes from the transcription analysis. Second, the researchers confirmed the relevance and usefulness of the initial major themes unanimously agreed upon through a process of virtually polling feedback from major stakeholders.

## Results

Qualitative data from focus group participants (n = 44) and key informant interviews (n = 18) were analyzed. The data revealed three primary themes: Distrust, Discrimination, and Social Determinants of Health (SDOHs). Each theme comprised subthemes as follows: For Distrust, the subthemes included (1) confidence in the healthcare professional, (2) provider empathy, and (3) active participation in healthcare decisions. Regarding Discrimination, the subthemes involved (1) racism and identity and (2) stigma related to diagnosis, disease state, and pain management. Lastly, for Social Determinants of Health, the key subtheme was the acknowledgment by providers that patients encounter competing priorities acting as barriers to care, such as housing instability and food insecurity. A total of 907 codes were identified in the transcripts. An analysis of the codes revealed that 35% were related to distrust while 55% of the codes were directly related to themes of discrimination. Social Determinants of Health accounted for 10% of the codes.

### Distrust

Trust plays a crucial role in patient-provider interactions, impacting the quality of care and patient outcomes,[8] as a crucial aspect of the healthcare system, it forms the foundation of the patient-doctor relationship. However, for patients of color, the definition and experience of trust can differ significantly. Many participants articulated that their recent interactions with the healthcare system were fostered by necessity rather than trust. Their interactions with providers were guarded and, in some cases, filled with anxiety. As one patient expressed:

> I have no trust in most of the doctors at (institution), no faith in them. And when I go there, I always look for one doctor. If she is not there, my anxiety kicks in so badly because I know that I'm not going to get the proper treatment and care that I'm supposed to get, and that's sad. (Rene, Focus Group participant)

Many participants cited negative experiences and dismissive attitudes toward patients that fostered distrust. Another participant described this recent encounter with her daughter's provider:

> Well, I don't trust doctors at all, just for the main fact that when my daughter was 10 years old, we were sent to see a specialist. They said they thought she had a hernia. The doctor came into the room. He didn't even examine my daughter; he just gave us the deed for the surgery, and I was like, "You didn't even examine her, so how are you so sure that it is a hernia?" (Patient, Focus Group Participant, Galaxy)

Some participants also reported that they were treated dismissively by providers and other healthcare staff. A Patient (Rene) stated, "(My) last visit was very humiliating. They talked to me like I was a street person." For some participants, dismissiveness manifested as a lack of empathy. These participants described situations in which patients

who were experiencing pain or discomfort were disregarded or made to wait a long time for help. One reported having to wait 2 hours to receive treatment for her asthma. Another participant witnessed a patient with a leg fracture asking for help to use the bathroom and being told to wait because the nurse was busy. A patient with incontinence described her misery and embarrassment when she overheard nurses making fun of her.

Other participants remarked that providers tended to diagnose and propose treatments without taking the patients' concerns and preferences into account. One such patient articulated their experience as follows:

> . . . and I noticed that my voice—it felt like my voice was not heard when it came to my requests and preferences of how I wanted to go through labor, how I wanted to experience my birth and delivery. It was a hard process. I remember going home after having a long conversation with my OBGYN at the time, crying to my husband because I felt like they owned my body, and like I was not someone who was being supported through my process. (Focus Group Participant, Ms. Fire)

Another patient described an adverse experience resulting from a provider's apparent failure to discuss the proposed treatment:

> The day that I gave birth . . . the doctor asked me "Are you feeling any pain?" I said no. He said, "Okay, I am going to take this envelope over to the emergency room, give it to the nurse . . . they're going to monitor you." And I'm, like, oh okay. My mistake was I did not read the letter, and the next thing you know, they told me I had an emergency C-section. (Focus Group Participant #5).

This lack of trust was also recognized and echoed by providers and medical students as a roadblock to achieving healthcare equity. The physicians were aware that some patients did not trust them. Interestingly, the providers did not blame the patients for this. Rather, they believed that current medical practices fueled this mistrust. A medical student articulated this as follows:

> I think a lot of the time it was because there was a lack of transparency. They weren't fully explained things, and they were like, things are just happening to them without them being involved in the discussion. . . whenever we're told about informed consent, we have to tell a patient all the different options, including no treatment, but that doesn't happen all the time, and they're kind of told, "This is what we're going to do, this is what's going to happen to you," and they're not really told all the risks and benefits—are not told all the options. So, I think that inherently brings distrust, and it's completely understandable. (Medical Student Focus Group Participant, Sam)

Despite the lack of trust in their physicians, the patients had a strong affinity with the hospitals within their community and looked for ways to improve their relationships with the hospitals. One participant described their relationship as follows:

> I think there's a love-hate relationship with the community and the hospitals. People call [Institution 1] (derogatory nickname), but they say they love [Institution 1]; that's their hospital. I think the same with [Institution 2]. People complain about the wait time or how they were treated not very nicely at [Institution 2], but that is their hospital—that's the hospital that they always go to. So I think it is a love-hate relationship between the community and hospitals. (Key Informant, TS)

Both patients and providers widely recognize that patients lacked trust in their healthcare providers. Lack of trust plays a huge role in healthcare inequity. According to a focus group participant, "If I trust my health provider, I will really be open to my health provider. I will give my health provider whatever information he or she demands."

## Discrimination

The second major theme that emerged from the data was discrimination, which consisted of two subthemes: Racism and identity, and stigma associated with diagnosis, disease state, and pain management. The study participants described discrimination in terms of the unique challenges and experiences that define how they perceive discrimination in healthcare.

## Discrimination Based on Racism and Identity

Racism's impact on access to quality health care was a major topic among the participants. Many participants cited that both implicit and explicit racism negatively impacted their receipt of care. Most of them conjectured that clinicians and hospital staff provide better care to white patients than to people of color. One patient recalled such an experience in the emergency department:

> I had already been admitted, and I saw a Caucasian guy come in. The way they catered to him was crazy. I even said something to the nurse, who replied, "Oh, I don't know. I don't have anything to do with that," but she noticed what was going on. They catered to him like he was president. (Patient Focus Group Participant, Rene)

Participants identified language as another aspect of discrimination, specifically, discrimination based on their inability to speak English. The participants witnessed and spoke about patients' struggles to effectively communicate in English, which resulted in patients not receiving care at all or receiving poor care. According to Galaxy,

> Recently, I was at ([Institution], I saw a Haitian man who couldn't communicate with the nurses being treated badly.

The staff neglected him because of his inability to speak proper English, and nobody was helping him. I wondered, "Why can't they get somebody who can speak Haitian to come and talk to him and see what his problem is?" But they just left him there. (Patient, Galaxy)

Participants also spoke about the need for sufficient access to translation services:

When I was at [Institution], I saw that they had the iPad translator. And I feel like they need to have those translators in more areas because I don't feel like people should die just because they can't express what's wrong with them, or what's hurting them. And I also feel like if you're in a certain neighborhood where, okay, there's more people that speak Spanish and more people that speak Creole in this area, then you should have people that speak these languages on hand. (Patient, Shantell)

### Stigmatization Associated with Diagnosis

Participants (aside from participants who are clinicians) reported that they experienced stigmatization from healthcare providers for their physical and medical conditions. They felt blamed for their current health and reported feeling stigmatized by healthcare providers for their diagnoses, especially regarding diseases associated with specific races, including uncontrolled diabetes and sickle cell disease.

They perceived providers' tendencies to focus on symptoms and blame patients for having those symptoms. Obesity was the most frequently reported condition that elicited this response. Providers tended to refer to patients with obesity as "fat" and recommended surgery without exploring the root cause of the condition. One patient recalled her experience with a doctor:

He said, "You're fat, you're overweight." I also have COPD and asthma, and I'm a diabetic. You know, when you take a lot of steroids, you gain weight, so they fix one problem, but some medications cause other problems, right? So, when I go to doctors, they tell me, "Oh, you're just fat. Have you ever thought about getting surgery?" What? (Patient, Rene)

Some participants reported being treated like drug addicts for requesting pain relief. They attributed this to being black skinned because they did not observe white patients being subjected to similar treatment. One participant described coming to the hospital with pain that did not respond to medication. After interrogating her about her medication use, the healthcare provider told her that she did not look like she was in pain. "And I'm like, well, what does pain look like?. . . What am I supposed to look like when I come here to justify the fact that I have a chronic illness?" (Key informant).

The participants reported that experiences of discrimination amplified the disconnect between the community, the patients, and the healthcare system. This also exacerbated the poor healthcare experiences suffered by many people of color.

### Social Determinants of Health

Social determinants of health encompass the social, economic, and environmental factors that impact patients' health outcomes.[29] The importance of addressing these health-influencing factors, as highlighted in key informant interviews and focus groups, was evident. The participant exhibited a solid understanding of social determinants of health, identifying relevant issues and proposing feasible solutions. In discussing SDOHs, most key informants cited various social factors that may undermine the effectiveness of the healthcare that patients receive. In the words of one key informant:

The procedure could be perfectly done, but if the patient goes home and can't get their medications, can't have proper nutrition, doesn't have adequate food, or can't be discharged safely because they don't have a home, these different SDOH's all contribute to their outcome. (Key Informant, Ms. E)

The participants generally agreed that it is the physician and staff's responsibility to consider SDOHs when creating a treatment plan for patients. A key informant (physician) described some relevant considerations:

All these different SDOH(s) are also contributing to their outcome. . . .. It's our duty to take the extra steps to not just manage their clinical pathologies, their actual disease, but also keep in mind the different things that come with the people in our community. They have high disease burden, chronic diseases, renal disease, cardiovascular disparities, and cancer, and so patients are coming from another country. (Key Informant, Ms. E)

Key informants also identified challenges faced by healthcare institutions in addressing SDOHs. In particular, the institutions faced shortages of staff and resources. Recognizing these challenges, the medical student participants reported that although they had been taught about the importance of addressing SDOHs, they had not been provided the tools and resources to help patients address their social needs.

The consequences of insufficient staff and resources on patient care were articulated by TS as follows:

I don't believe we are practicing comprehensive holistic approach to our patients. In the most ideal world, they would have a social worker that can track the patient, follow-up with the patient at the discharge, making sure that the patient has a

place to go to heal, a safe space or a home, or connect them with some sort of shelter system and then track them to make sure they have their medications, that they are set up for follow-up appointments, and plug them up into a system. I am not sure whether that exists anywhere. . ., but we surely don't have it here.. . . Some of them may not have job security, food security to ensure they have money to even pay for the medication. . .. What we end up seeing, particularly in the emergency department, is the breakdown of the outcomes of that, so how are we impacting the SDOH? I don't think we are doing a good job because we don't have enough services. (Key Informant, TS)

Furthermore, informants reported that because of insufficient staff, doctors are compelled to perform the duties of other staff in addition to their own. For solutions, participants called for increased collaboration with community-based partners to increase the capabilities of healthcare facilities to address both the medical and social needs of patients. Otherwise, referrals for other healthcare services might be ineffective:

Even though clinicians would readily refer a client and not know or seek to know the outcome of that referral. . . they feel, "Problem solved not," but clients may not even connect with the places they send them. It may be inconvenient. It might be too much. They may not understand. They may have nowhere to go, and that may be too busy, so if that referral never reaches an organization that can really reach that client, the referral that the doctor made is just that. It's just a referral with nothing. (Key Informant, Ms. Africa)

Participants shared that having understanding staff, peer navigators, community health workers, and other staff with similar community-linked roles will help facilities meet the social needs of their patients.

## Discussion

This study was conducted as part of survey development, with the initial step consisting of formative qualitative interviews. In this first phase of the BKHI project, we used Interpretative Phenomenological Analysis to explore the lived experiences of 62 participants across the healthcare spectrum. The health equity implementation framework guided our epistemological stance, which aided in the interpretation and analysis of the participants' nuanced and multilayered narratives of their experiences, which impacted health equity.

We report on three themes: distrust, Discrimination, and SDOHs. For the first theme, participants' interactions with the healthcare system were prompted by a necessity for medical attention, and not by trust. Although most described this lack of trust as having deep historical roots,[8] the

participants recognized that, if not addressed, distrust can have severe repercussions for health equity, such as delayed treatment, inadequate follow-up on medical advice, and worse health outcomes. The issue of distrust was acknowledged by both the providers and the patients; however, they had differing views on how to resolve this. The patients sought pragmatic and positive interactions with providers, such as displaying respect, empathy, and genuinely listening to patients' concerns or issues. Meanwhile, providers focused on the need to change current medical practices, which are still deeply influenced by racism.[20] While our findings align with numerous studies on trust and health outcomes,[8,30] our research further contributes to the existing knowledge that trust issues and the resolutions sought by patients and providers are viewed differently.

The second theme centered on discrimination, which the participants observed from the mediocre quality of care and worse health outcomes they received when compared to their counterparts. In narrating their experiences, they described racism as a major roadblock to health equity. In their interactions with the healthcare system, the participants experienced discrimination based on identity, which they believed resulted from the color of their skin and the language difficulties they faced. Racism is now seen as a public health crisis,[26] and our findings add to existing studies confirming that there are long-standing concerns about discrimination, and that structural racism shapes the healthcare of black and brown patients.[20,31]

Most of the participants reported being stigmatized and blamed for their medical conditions, particularly those of patients with obesity, diabetes, or sickle cell disease. Our results mirror Sun et al.'s[32] analysis of the electronic records of 18,459 adults. They found that physicians were more likely to use stigmatizing language and descriptive terms such as "refused," "not compliant," "agitated," and "not adherent" in black patients' records than in white patients' records. Based on their analysis, the researchers reported that patients whose physicians tended to judge and blame them were much less likely to trust their doctors. Stigmatizing labels can also cloud a physician's judgment and decision-making, which could impact care delivery and further deepen distrust.

As noted by the study participants, discrimination in its many forms impacts the way healthcare is delivered and accepted, as well as its effectiveness. As noted elsewhere, "health and healthcare disparities are often viewed as the lens of race and ethnicity."[2] Our findings contribute to the body of research highlighting the link between racism and health disparities.[7,31] This is consistent with Paradies Y's systematic review, which examines the relationship between self-reported racism and health outcomes across diverse populations and countries.[33] Their meta-analysis, which includes 293 studies conducted in the US between

1983 and 2013, also supports our findings of a significant detrimental impact of racism on the health outcomes of people of color.

Although utilizing the same interview guides to explore the perspectives and understanding of SDOH from both staff and patients, it is interesting to note that medical students, clinicians, and key informants spoke about it more than the patients. One possible reason for this difference could be that stakeholders and clinicians have a deeper understanding and awareness of the impact of social determinants on health outcomes due to their training and experience, compared to the patients. Additionally, staff members may have a different perspective and knowledge base due to their professional background and exposure to diverse patient cases. However, both patients and staff described patient experiences regarding the shortage of staff, lack of resources, and weaknesses of healthcare facilities in addressing these unmet needs when discussing SDOH. To our knowledge, the difference in perceptions about social determinants of health between patients and providers has not been reported in previous SDOH studies.[34,35] Currently, only a one-sided view with more input from providers is available in the literature.[29] This divergent view calls for a more comprehensive discussion of social determinants during interviews with staff and patients when a patient-centered intervention on SDOH is warranted.

This study used a participatory, community-based approach to understand and assess how patients of color within a community experience health equity within the healthcare system. Our study echoes the true definition of patient of color experiences as the "sum of all interactions, shaped by an organizational culture that influences patient perceptions, and the importance of considering across the continuum of care."[2] The participants in this study emphasized that health equity is not only about healthcare access; it is also about elements of human beings caring for human beings.[2] This is why, beyond clinical engagement, our participants spoke to feelings of being discriminated against, and the need for respect, improved communication, and shared healthcare decision-making.

Health equity matters to these participants. Within this concept, the participants spoke about the "love–hate relationship" with the healthcare system within their communities. They were proud of being associated with their community hospitals and wanted to receive care from "their hospital rather than going across the bridge," but they had a hate relationship with the hospital due to feelings of disengagement on the part of the hospital. Beyond caring for their medical and physical health needs, the participants desired positive patient experiences that led to good outcomes. Health equity matters to them, as demonstrated by their willingness to speak up and offer suggestions for fostering positive patient experiences.

## Limitations

There was potential selection bias in our sample of participants who may have had negative experiences with the healthcare systems. A major limitation of qualitative research is that it provides contextual insights into the experiences of a limited number of people in specific settings. Our study findings were limited to capturing only the experiences of patients living in Central Brooklyn and may not be representative of the experiences of other people of color and their healthcare systems. Finally, the use of Zoom rather than in-person interviews meant that our findings were restricted to participants with access to technology and may exclude poor patients.

## Conclusion

The participants' collective knowledge showed evidence of varied understandings and perceptions of health equity, emphasizing the urgent need to address patient of color experiences in a manner that contributes to ending health inequity. Our findings suggest that unless the issues of mistrust, discrimination, and inadequate patient–provider relationships in dealing with SDOHs are addressed, the gap between patients of color and providers will continue to grow, resulting in less engagement with the health-care system and a vicious cycle of health imbalances. It is not enough to provide medical access to the community; if patients of color and their community are to fully engage with the health-care system, they must be able to trust it and not feel discriminated against. Using the health equity implementation framework, we also identified the key drivers of health inequities among those surveyed: mistrust, discrimination, and social determinants of health. Therefore, it is essential for clinicians, hospital management, and policymakers to develop and implement strategies to address these conditions with the aim of promoting equity for all health-care consumers. Institutions must focus on system-level changes to address structural racism which is at the basis of health inequity.

## Implications for Policy and Practice

Healthcare leaders must take decisive and concrete steps toward quality improvement initiatives that reduce or eliminate structural racism, enhance patient care, and improve patient outcomes, particularly for marginalized communities. Implementing health system improvements based on patients' of color feedback regarding their unique experiences when seeking care is an important step toward achieving a more equitable health-care system.

## Declaration of Conflicting Interests

## Funding

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## References

1. Ndugga N, Artiga S. *Disparities in Health and Health Care: 5 Key Questions and Answers*. Kaiser Family Foundation; 2021: 11.
2. Wolf JA, Niederhauser V, Marshburn D, LaVela SL. Reexamining "defining patient experience": the human experience in healthcare. *Patient Exp J*. 2021;8(1):16-29.
3. Bertakis KD, Azari R. Patient-centered care is associated with decreased health care utilization. *J Am Board Fam Med*. 2011;24(3): 229-239.
4. Goldstein E, Farquhar M, Crofton C, Darby C, Garfinkel S. Measuring hospital care from the patients' perspective: an overview of the CAHPS® hospital survey development process. *Health Serv Res*. 2005;40(6p2):1977-1995.
5. Shen MJ, Peterson EB, Costas-Muñiz R, et al. The effects of race and racial concordance on patient-physician communication: a systematic review of the literature. *J Racial Ethn Health Disparities*. 2018;5(1):117-140. doi:10.1007/s40615-017-0350-4
6. Phelan JC, Bruce GL. Is racism a fundamental cause of inequalities in health? *Ann Rev Sociol*. 2015;41:311-330.
7. Bailey ZD, Krieger N, Agénor M, Graves J, Linos N, Bassett MT. Structural racism and health inequities in the USA: evidence and interventions. *Lancet*. 2017;389:1453-1463.
8. Griffith DM, Bergner EM, Fair AS, Wilkins CH. Using mistrust, distrust, and low trust precisely in medical care and medical research advances health equity. *Am J Prevent Med*. 2021;60(3):442-445.
9. Jones CP. Levels of racism: a theoretic framework and a gardener's tale. *Am J Public Health*. 2000;90(8):1212-1215.
10. Collins PH. *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. Routledge; 2022
11. Bhopal K. *White Privilege: The Myth of a Post-racial Society*. Policy Press; 2018.
12. Stoler AL. *Duress: Imperial Durabilities in Our Times*. Duke University Press; 2016.
13. Vahidy FS, Nicolas JC, Meeks JR, et al. Racial and ethnic disparities in SARS-CoV-2 pandemic: analysis of a COVID-19 observational registry for a diverse US metropolitan population. *BMJ Open*. 2020;10(8):e039849. doi:10.1136/bmjopen-2020-039849
14. Moore JT, Pilkington W, Kumar D. Diseases with health disparities as drivers of COVID-19 outcome. *J Cell Mol Med*. 2020;24(19):11038-11045. doi:10.1111/jcmm.15599
15. Renelus BD, Khoury NC, Chandrasekaran K, et al. Racial disparities in COVID-19 hospitalization and in-hospital mortality at the height of the New York City pandemic. *J Racial Ethn Health Disparities*. 2021;8:1161-1167. doi:10.1007/s40615-020-00872-x
16. 7. Lieberman-Cribbin W, Tuminello S, Flores RM, Taioli E. Disparities in COVID-19 Testing and Positivity in New York City. *Am J Prevent Med*. 2020;59(3):326-332. doi:10.1016/j.amepre.2020.06.005
17. Moore JT, Ricaldi JN, Rose CE, et al. Disparities in incidence of COVID-19 among underrepresented racial/ethnic groups in counties identified as hotspots during june 5-18, 2020 - 22 states, february-june 2020. *MMWR Morb Mortal Wkly Rep*. 2020;69(33):1122-1126. doi:10.15585/mmwr.mm6933e1
18. Phillips N, Park I-W, Robinson JR, Jones HP. The perfect storm: COVID-19 health disparities in US Blacks. *J Racial Ethn Health Disparities*. 2021;8(5):1153-1160. doi:10.1007/s40615-020-00871-y
19. Qiao WP, Powell ES, Witte MP, Zelder MR. Relationship between racial disparities in ED wait times and illness severity. *Am J Emerg Med*. 2016;34(1):10-15. doi:10.1016/j.ajem.2015.08.052
20. Gee GC, Ford CL. Structural racism and health inequities: old issues, new directions. *Du Bois Rev*. 2011;8(1):115-132.
21. Williams DR, Lawrence JA, Davis BA. Racism and health: evidence and needed research. *Annu Rev public Health* 2019; 40:105-125.
22. Paradies Y, Ben J, Denson N, et al. Racism as a determinant of health: a systematic review and meta-analysis. *PLoS One*. 2015;10(9):e0138511.
23. Mitchell JA, Williams E-DG, Li Y, Tarraf W. Identifying disparities in patient-centered care experiences between non-Latino white and black men: results from the 2008-2016 Medical Expenditure Panel Survey. *BMC Health Serv Res*. 2020;20(1):495. doi:10.1186/s12913-020-05357-5
24. Hinterland K, Naidoo M, King L, et al. Community health profiles 2018, Brooklyn community district 14. *Flatbush Midwood*. 2018;38(59):1-20.
25. New York City Department of Mental Health and Hygiene. New York City Community Health Profiles. 2023. http://www1.nyc.gov/site/planning/community/community-portal.page
26. Zraick K. Racism is Declared a Public Health Crisis in New York City. 2021. https://www.nytimes.com/2021/10/19/nyregion/nyc-racism-healthcaresystem.html?searchResultPosition=14#after-story-ad-2
27. Woodward EN, Singh RS, Ndebele-Ngwenya P, Melgar Castillo A, Dickson KS, Kirchner JE. A more practical guide to incorporating health equity domains in implementation determinant frameworks. *Implement Sci Commun*. 2021;2(1):61.

28. Maxwell J. Understanding and validity in qualitative research. *Harvard Educ Rev*. 1992;62(3):279-301.

29. Palacio A, Seo D, Medina H, Singh V, Suarez M, Tamariz L. Provider perspectives on the collection of social determinants of health. *Popul Health Manag*. 2018;21(6):501-508.

30. Kennedy BR, Mathis CC, Woods AK. African Americans and their distrust of the health care system: healthcare for diverse populations. *J Cult Divers*. 2007;14(2):56-60.

31. Ben J, Cormack D, Harris R, Paradies Y. Racism and health service utilisation: a systematic review and meta-analysis. *PLoS One*. 2017;12(12):e0189900.

32. Sun M, Oliwa T, Peek ME., Tung EL. Negative patient descriptors: documenting racial bias in the electronic health record: study examines racial bias in the patient descriptors used in the electronic health record. *Health Affairs*. 2022; 41(2):203-211.

33. Paradies Y. A systematic review of empirical research on self-reported racism and health. *Int J Epidemiol*. 2013;2:105-138.

34. Schoenthaler A, Hassan I, Fiscella K. The time is now: fostering relationship-centered discussions about patients' social determinants of health. *Patient Educ Couns*. 2019;102(4): 810-814.

35. Sokol RL, Ammer J, Stein SF, Trout P, Mohammed L, Miller AL. Provider perspectives on screening for social determinants of health in pediatric settings: a qualitative study. *J Pediatr Health Care*. 2021;35(6):577-586.