

How Perceived Structural Racism and Discrimination and Medical Mistrust in the Health System Influences Participation in HIV Health Services for Black Women Living in the United States South: A Qualitative, Descriptive Study

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Abstract

There are racial and geographic disparities for HIV in the United States; Black women have nearly 20 times the risk of White women in being infected with HIV, and lifetime HIV risk is greatest for people living in the southern United States. These disparities, layered with the structural racism and discrimination that is more prominent in the south, is a public health issue. The purpose of this article is to share Black women's perspectives of how perceived structural racism and discrimination, and medical mistrust in the health care system contribute to their participation in health services. In this formative study, we conducted seven focus groups among women living in 10 low-income housing communities. Results indicate that there are barriers to the utilization of health services that are grounded in personal experiences and historical mistrust for the health care system. Understanding these barriers is critical to combating the HIV epidemic for this population.

Key words: Black women, health care utilization, medical mistrust, qualitative study, structural racism and discrimination

The southern region of the United States is disproportionately affected by HIV, having twice as many new HIV diagnoses compared with other regions (Center for Disease Control and Prevention [CDC], 2016). High poverty rates, poor quality health care, and low rates of insurance coverage have all been linked to HIV prevalence (CDC, 2016; Hess et al., 2017) and contribute to the higher rates of HIV infection in the US South. Additionally, racism and discrimination, and medical mistrust are more profound in the U.S. South, due to its unique social–historical legacy, which includes economic oppression, slavery, racial discrimination, and segregation (Barr, 2014; Bradley et al., 2018; Institute of Medicine, 2003).

Furthermore, among all women, Black women account for the largest share of new HIV diagnoses (57% in 2019). The rate of new diagnoses among White women in 2019 was 21% and the rate among Latinas was 18% (CDC, 2019). In addition to racial and regional disparities, Black women living in low-income communities have a 5-fold increased incidence of HIV infection than the general population of Black women (Frew et al., 2016; Hodder et al., 2013). This increased incidence, layered with the structural racism and discrimination that is more prominent in the southern region of the United States, is a public health issue of great concern.

Examination of the impact of structural racism and discrimination on health decision making of marginalized groups, such as low-income Black women, is integral to elimination of health disparities and promotion of health equity. Structural racism refers to “the totality of ways in which societies foster racial discrimination through mutually reinforcing systems of housing, education, employment, earnings, benefits, credit, media, health care, and criminal justice; these patterns and practices in turn reinforce discriminatory beliefs, values, and distribution of resources” (Blair et al., 2013, p. 1). Structural discrimination refers to policies that are race or gender neutral in intent but have negative effects on women, minorities, or both (Pincus, 1996).

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To effectively address the HIV disparities that exist for Black women, it is critical to contextualize women's perspectives of structural racism and discrimination within broader systems of racism (Bailey et al., 2017; Blair et al., 2013). Understanding how structural racism and discrimination influence efforts to develop and implement viable strategies to protect Black women from acquiring HIV and maximize care for women living with HIV is critical to stemming the devastating effects of this health issue on Black women and the larger community. Much evidence exists regarding the impact of individuals' self-reported experiences of individual-level racism and discrimination on their health (Blair et al., 2013). In contrast, little is known about the experiences of those most affected by the HIV epidemic related to structural racism and discrimination in the health care system.

In addition to racism and discrimination and its impact on health care decision making and medical mistrust continues to have an impact on health and health outcomes of the Black community (Pellowski et al., 2017). It is critical to take into consideration how historical medical mistrust compounds the challenge of addressing the HIV epidemic, specifically in the US South. Medical mistrust has been shown to be negatively correlated with medication necessity beliefs and has been found to lower medication adherence, especially for Black individuals living with HIV (Pellowski et al., 2017). Additionally, in multiple studies exploring HIV prevention in Black women, women reported medical mistrust as a barrier for not discussing or accessing HIV prevention medications such as pre-exposure prophylaxis (Flash et al., 2014; Goparaju et al., 2017).

There are few HIV prevention interventions designed specifically for Black women who are socially and culturally relevant and who consider the effect that structural racism and discrimination, and medical mistrust, have on HIV prevention and treatment services. There is a need for gender-specific, culturally salient interventions and services for Black women to optimize their health care decisions, health outcomes, and participation in HIV prevention interventions and programming. In a larger, primary study, we identified that the perceptions of Black women about structural racism and discrimination, and medical mistrust, were critical to the development of HIV prevention programs and interventions. The purpose of this study was to share Black women's perspectives of how perceived racism and discrimination, and medical mistrust, in the health care system contributed to their participation in health practices and programs.

Methods

In this qualitative descriptive study, we conducted seven focus groups among African American women living in 10 low-income housing communities from July 2016 to October 2016. We conducted one more focus group in March 2017 to verify saturation of themes. Focus groups were conducted in private spaces such as the community center at the public housing authority or public library. Focus groups were primarily conducted by two racially congruent facilitators (African American women) who had backgrounds in public health and grew up and still live in the geographical areas where this research was conducted. Additionally, two White women, who were researchers from the university, were also data collectors. Written consent was obtained from each participant. The study design, including data collection tools and analytic approach, was guided by a conceptual model that was based on the Gelberg-Andersen Behavioral Model for Vulnerable Populations of Health Care Utilization (Gelberg et al., 2000). The model shows the relationships among health systems, the external environment, and predisposing, enabling, and need characteristics of the population that lead to the use of health programming and personal health choices which, in turn, affect HIV risk.

With this conceptual model as a guide, the focus groups were designed to elicit the perspectives of Black women, who were public housing residents, regarding barriers to HIV prevention practices and underutilization of health programming. More specifically, examples of questions that we asked participants to guide data collection included the following: "What is most important to you about your own health?," "If you had the chance to design the perfect health program, what would it look like? What would it have?," and "How do you see an HIV prevention program being helpful or unhelpful within this community?" We did not specifically ask about structural racism and discrimination, and medical mistrust, in our focus groups because these concepts were not directly examined in this study. However, in our analysis of the transcripts of the primary study, perceived structural racism and discrimination, and medical mistrust, of the health care system were uncovered as barriers to Black women receiving and engaging in preventive care and treatment.

The study methods were developed and conducted by a community-academic partnership (CAP), which consisted of a group of researchers and other academic partners ($n = 10$), representatives from the local public housing authority ($n = 2$), a community-based organization ($n = 3$), community stakeholders ($n = 8$), and Black women living in low-income housing communities

($n = 10$). Member selection for this group included those who had an interest in supporting HIV prevention in African American/Black communities, who had an existing relationship with or were referred to the research team and who were willing to convene a minimum of three times per year for approximately 90–120 minutes per meeting. The overall purpose of the CAP was to make study design decisions, including adapting an HIV prevention program, providing input on focus group guides and survey instruments, and developing the implementation plan and pilot evaluation. Participation in the CAP included capacity-building activities in research and community engagement activities.

Participants in the focus groups all self-identified as African American/Black women, 18 years or older, who were residents of one of 10 public housing developments in one small southeastern city. There were no cultural variations reported by participants such as Afro-Caribbean or Native African. For the purposes of this study, which focused on primary prevention approaches for women who were not infected with HIV, we did not ask women about their HIV status to avoid any stigmatization that could occur related to HIV. Study staff posted recruitment flyers in local public housing authority community centers and attended community events, including monthly resident council meetings to invite women to participate. CAP members provided referrals for community-based snowball sampling to identify potential participants who were then screened for eligibility by study staff. There were 3–12 women participants in one of the seven focus group discussions.

Traditionally, in marketing research, the ideal size of a focus group to obtain reactions to a product is considered to be 10–12 people (Stewart & Shamdassani, 2015). For the purpose of exploring an issue or behavior, 6–8 is preferred (Stewart & Shamdassani, 2015). As one of the main purposes of the larger study, in our focus groups, we aimed to obtain women's reactions to features of an HIV prevention program to which they had not been previously exposed, and we elected to allow our focus group size to include as many as 12. The selection of the range for the sample size of our focus groups took into account the study purposes, as well as logistical considerations, and the need to maintain trust and good rapport with the communities in which we were conducting research. No information was collected regarding whether participants identified as cisgender or transgender women. Each focus group was conducted by one facilitator, one co-facilitator, and one note taker. Four researchers took turns serving as facilitator, co-facilitator, or note taker at each focus group. Three other

research staff served as note takers and assisted with administrative aspects of the study.

Data were analyzed using a conventional content analysis method (Hsieh & Shannon, 2005). In this method, concepts are directly derived from data. All focus groups were audiorecorded and transcribed verbatim by a professional transcription company, with identifying information redacted. A team of three qualitative researchers used Atlas.ti Version 8 software to manage the transcribed data while analyzing the transcripts collaboratively. The team reviewed the transcripts and created a preliminary codebook of topical and interpretive codes derived from common words, statements, and themes in the transcripts. Interpretive codes were applied to ideas that were expressed but not explicitly queried or stated (e.g., trust, motivation). The team applied topical and interpretive codes to significant utterances exemplifying each code and compared results with assess consistency between coders. Where there was disagreement among coders, topics were discussed further to achieve consensus to develop a final codebook. Researchers used the final codebook to code the transcripts and examined codes and quotations for clusters of meaning related to contextual factors that influenced women's use of HIV prevention practices and programs. Attention was given to points of overlap and contrast within and among each discussion. We sought data saturation (as opposed to theoretical saturation), when the data collectors were hearing the same or similar comments again and again (Saunders et al., 2018). After preliminary review of the focus group tapes, we conducted one more focus group in March 2017, to ensure that no new information was being discussed that had not been heard in the previous focus groups.

Trustworthiness of findings included five primary strategies (Miles et al., 2019). They included (a) bracketing: temporarily setting aside the researchers' assumptions (by having detailed, reflective discussions about data) and creating an audit trail of analyzed data, (b) precise data analysis: providing rich descriptions to convey the findings, (c) external audit: asking a person outside the project to conduct a thorough review of the study results, (d) member checking: getting feedback from the community advisory panel and a subsample of women participants on the accuracy of the identified categories and themes, and (e) data checking two other data sources from the same community of women participants (a survey and the photo voice project not reported here) enabled us to triangulate our findings. All study methods were approved by the University of North Carolina at Chapel Hill's Institutional Review Board

and the Office for the Protection of Human Subjects (IRB protocol number 15-1386).

Results

Forty-eight women meeting eligibility criteria participated in this study. The ages of the women ranged from 30 to 60 years. Participants shared their health encounters from multiple experiences with the health care system, including interactions with a variety of disciplines (physicians, social workers, nurses), with the idea that such experience could potentially translate into ways to enhance participation by Black women in HIV prevention programming. A prominent theme that emerged somewhat unexpectedly throughout the data was women's perceptions of structural racism and discrimination, and medical mistrust, as barriers to receiving and engaging in preventive care and treatment. Although the words "structural racism and discrimination and medical mistrust" were not directly used by participants throughout the interviews, the researchers made the connections between individual experiences discussed in the focus groups and broader structural issues of race. The concepts of structural racism and discrimination, and medical mistrust, were consistently communicated by women as being significant factors in their health care decisions and program participation.

Four subthemes emerged from our analysis of these focus group discussions related to Black women's perceptions of structural racism and discrimination, and medical mistrust. These included the following: (a) previous experiences with the health care system decreased women's trust in health care providers' medical advice and instructions; (b) systems and structures place Black women at a disadvantage compared with White women; (c) women perceived that providers lacked effective communication with Black women in the clinical encounter; and (d) women need to be empowered in the clinical encounter with health care providers. Individual quotes from participants are reflected in each theme to further describe participants' perspectives and insights.

Previous Experiences of Women With the Health Care System Decreased Their Trust in Health Care Providers' Medical Advice and Instructions

Participants expressed their distrust of medical providers. This distrust stemmed from various sources. For example, women shared their perceptions that providers give false medical information to patients who are Black. The following quote provides an example from one participant of how misinformation from health care providers leads to negative perceptions of them,

They said, "Oh you might have an STD." So what we're going to do is we're going to treat you. And I came back with no STD. So you're not treating me? First of all, you falsely medicated me. You're taking insurance money that don't need to be used. I just think the program is a bit crazy.

In addition, women viewed certain health care facilities as being more trusted and trustworthy than others based on their perception of receptivity toward Black patients. Women identified certain facilities by their geographical location as being trustworthy or not. One participant told of her experience at a health care facility not located in an affluent community: "I think because they think we're Black and ignorant, and they can tell us anything and we going to fly with it."

Another participant stated, "Girl, [Name of Institution] is trying to kill people. I'd rather go to my [Name of second institution] and I know I'll get care and stay alive." Participants perceived the first medical establishment as a historically White institution and described how their experiences of bias toward them from providers in this institution affected how they received and followed guidance from the providers. Not only does this suggest the severity of the perceived racism but also that some providers or institutions are perceived as worse than others.

In some cases, women's mistrust of the health system caused skepticism toward medical advice and contributed to their engaging in behaviors that lead to negative health outcomes. In reference to trusting medical advice from providers in the health system, one focus group participant shared,

I don't wanna say it like this, but even when we go to the doctor, the White people's terminology, Eat healthy, don't smoke, don't do drugs, protect your sex or abstinence...I smoked cigarettes the whole 9 months. I even smoked a little weed the whole 9 months...And I drank some beer the whole 9 months. My baby—my last baby—was 9 pounds...So I don't know what he's talking about.

The perception that this was "White terminology" led this woman to not believe and trust what she was told by health care providers, mainly because the information did not hold true for her lived experiences.

Systems and Structures Place Black Women at a Disadvantage Compared With White Women

Participants perceived that institutional and systematic regulations contributed to women's mistrust of the health care system.

I had heard they were going to start giving people who get food stamps drug tests. They're afraid of the drug tests [referring to low-income Black women]. So they avoid going to the doctors and to the hospitals completely.

Systematic policies, especially in low-income housing, have a direct impact on other facets of life for women, including their health care decisions. Structural factors related to the public housing environment present additional barriers to social cohesion, racism, and competing priorities, as one participant explained:

The government, who decides what type of taxes we can afford, what type of lifestyle we can have, how much money we can make, whether you're a woman or a man, Black, White, Asian, whatever. That plays a lot in what a person has to go through, especially women. They had to fight so hard and so long to make women's rights an issue and become the status that we are today, especially if we're Black. It's much, much harder to even make the kind of money you want to.

This participant expresses the systematic inequities of women in general but adds that being a woman and Black adds a layer of challenges to accessing health care. For example, women discussed the lack of insurance, which made them unable to afford health care. One participant stated,

The health department is the health department, meaning they are there to help people. But now they will not see you unless you can pay. Why do you have to pay to go to the health department? You used to could walk in and say I have a STD and they would go ahead and see you.

Women expressed little to no resources in the community to access affordable health care. They stated that even for the clinics that are labeled as free or affordable, they have co-payments that make accessing care challenging.

Lack of Effective Communication in the Clinical Encounter

Women perceived a lack of communication within and across the health care system as evidenced by the difference in the care received at hospitals or clinics based on their geographical location. Women also stated that they experienced challenges with communication with health care providers in the clinical encounter, such as receiving misinformation or having the provider not communicate the details of the care being given.

I walked around with cancer for 3 years...I went to the doctor back and forth. Nobody never spoke of these things. I was in an all-girls home, going to the doctor regularly. Nobody ever spoke of me having this. When I came back to [name of facility] to the health department, they was like, we've been looking for you for 3 years. We wanted you to know you got cervical cancer.

In another example, this woman describes the provider's communication style as "lacking"; the provider did not elaborate on the care to be given nor provide detailed explanations. The woman explained, "They [health care

providers] don't communicate. Hey, we're going to give you this shot. It's birth control. Here you go."

Finally, women reported cultural norms that may exist among Black women, which can potentially influence their seeking of care. For example, one participant stated,

Most people, they don't go to a health seminar. They don't want to know if something is going to happen to them. They don't do it unless something is wrong with them. I don't want to talk to a doctor unless I'm sick.

Although many women reported negative experiences with provider communication, there were a few who acknowledged effective provider communication. These positive provider-patient communications show that when time and care are taken by providers to establish good communication and relationships, health behaviors can improve.

Black Women Perceive the Need to be Empowered in the Clinical Encounter With Health Care Providers

The perceived racial bias of health care providers has been a motivating factor for women to advocate for their rights. The quotation below provides an illustrative example of how women are propelled, once again, to question health care recommendations and also to demand more from their providers:

"But see, us Black people have to start being more aware ourselves. We got to start asking questions. You can't just stick me in my arm with anything no more."

One woman shared how her experiences in the clinical encounter have caused her to be more aware of the care provided or recommended to her. She explained how she has changed her communication with her health care provider to be more assertive.

A doctor can't give me nothing now. I want to know what's in the shot. "Excuse me, what's this shot?" "Oh, it's going to cure you." "No, what is it? What's the name of it? What are the side effects?" A lot of stuff nobody tells us.

Another woman explained how she began to research birth control options given to her and other health care recommendations, "Literally I started doing the research, started doing my own research." In agreement, another participant stated, "They don't communicate." Women expressed the need to investigate their own health care due to the lack of in-depth communication they experienced in their clinical encounters. The need to understand health care treatments was essential to women's decision making regarding their health.

Discussion

Structural racism and discrimination have been shown to affect the health and well-being of individuals in complex, multifaceted ways (Bailey et al., 2017; Blair et al., 2013; Institute of Medicine [IOM], 2003). In this study, women living in low-income housing indicated a number of ways that they perceived that structural racism and discrimination impeded their abilities to access health care and preventive services and to carry out certain health behaviors. One of the most salient themes to emerge from their stories was their mistrust of health care providers and institutions, a finding that is consistent with other literature on mistrust of medical systems among minorities (Bailey et al., 2017; Blair et al., 2013). Participants described examples of their interactions with health service providers and, in a number of cases, were able to explicitly articulate how they felt those interactions affected their level of knowledge and understanding of their own medical conditions, risks, and treatment, and their personal health behaviors. Some women reported examples of interactions with providers and perceptions of the health care system that had no direct reference to race alone, but their underlying perspectives were that being Black and a woman added layers to their existing challenges with health care systems. Also consistent with other studies is that low-income Black women report lower receipt of medical risk information and health advice from physicians compared with higher income and non-minority women (Flash et al., 2014; Frew et al., 2016).

These findings have expanded our understanding of Black women's skepticism of medical providers and systems and have reinforced our view of the importance of addressing these trust issues in future HIV prevention efforts with this population. Failure to do so risks continuing the cycles of medical distrust leading to poor health outcomes. HIV programs serving Black women should include conversations around race and trust for both providers and patients.

In addition to the individual experiences of perceived discrimination that women in this study shared, some participants also drew attention to the less overt and less identifiable acts of racism that are built into health care systems. Similarly, Feagin and Bennefield (2014) assessed decades of empirical research on racial dimensions of US health care and public health institutions. Consistent with women's reports in our study about interpersonal relationships within the health care system, Feagin and Bennefield (2014) concluded from research that "institutionalized White socioeconomic resources, discrimination, and racialized framing from centuries of slavery, segregation, and contemporary White oppression

severely limit and restrict access of many Americans of color to adequate socioeconomic resources- and to adequate health care and health outcomes" (p. 7). This long history will require that critical conversations about race and health take place to begin breaking deeply ingrained cycles of discrimination. Bringing awareness to providers and administrators about the roles they play in this broader system, which affects the health of minority women, is essential. Awareness is the first step toward modification of provider behaviors and institutional policies that can then lead to better patient health outcomes. Integrating trainings on race, trust, and implicit bias into HIV programming and interventions for all stakeholders is strongly recommended. If meaningful progress is desired toward reducing HIV disparities among Black women, focusing on health systems and individual providers becomes important.

Women in our study also provided further context on the broader social environments of Black women in the South and reported that the systems and environments in which they live have a significant impact on their health care beliefs and decisions. Consistent with the findings from the Institute of Medicine report, "Unequal Treatment" (IOM, 2003), our study with Black women highlighted disparities that stem back to the social environments in which they live, work, study, and engage in other activities. For example, employment, neighborhood characteristics, and social policies as well as culture and beliefs about health all influence health care decisions and outcomes. In our study, women perceived that providers judged them based on the combination of their race and class (low-income status). The perception was that perceived discrimination was worse because they were Black, women, *and* low-income. There is synergy between classism and racism that makes the racism worse for low-income individuals. Even if not overt, women perceive race to be a factor in their encounter with health care systems.

It is critical to also acknowledge that not only do employment, neighborhood characteristics, social policies, culture, and beliefs about health influence low-income Black women but also they influence decision makers in the health care system, as well as government, policy makers, and developers of health care interventions and programs. Their culture and beliefs also affect the decisions they make and the interactions they have with low-income Black women, further reinforcing the need for race and equity training and raising awareness among a diverse range of stakeholders (Black et al., 2019).

Finally, positive communications in the clinical encounter and in health care programming are essential components of building and restoring trust among Black women. Disparities between women of color and White women in their experiences of interacting with providers

in clinical settings have been shown to lead to poorer health among Black women (Barr, 2014; Bradley et al., 2018). Our findings were consistent with other studies that found that racial and ethnic minorities report poorer communication and lack of shared decision making, greater distrust, and discrimination and ultimately experience poorer health. As the setting where medical decision making occurs, the clinical encounter is a tangible window of opportunity for providers and health systems to positively impact the health of Black women (Bailey et al., 2017; Blair et al., 2014; Castle et al., 2018; Hall et al., 2015). Identifying trusted individuals or gatekeepers in the communities where women live also are essential in linking women in the community to the needed health care clinics, programs, information, and other resources.

Participants explicitly expressed a preference for HIV-related messaging and programming to be delivered by community members, as opposed to clinicians, who they perceived to be more relatable. Peer education interventions are also strongly recommended. Participants in our study revealed examples of service providers who have successfully established open and respectful relationships, which suggest that in cases where trust between clinicians and patients is established, preventive health behaviors can be improved.

As in all studies, this study has limitations. We did not differentiate women by gender identity (cis- vs. transgender); thus, it is not known if gender was associated with differential effects. Future studies should include the perspectives of this population to determine their experiences and the impact of their experiences on health care decisions and engagement in programs.

These findings support the importance for health care providers, as well as researchers, to be aware of systematic racism and structural discrimination that may be overt in our health care systems. Additionally, these systems may cause providers to translate implicit actions into the clinical encounter with patients and their families, as well as in intervention and program development. It is critical to have conversations, trainings, and workshops about these concepts and develop strategies to address them. For example, engaging women in the development, implementation, and evaluation of clinical services and programs that directly influence them would be critical for assuring that the services provided are culturally and socially relevant.

There is no simple solution to addressing the sensitive nature of perceived systematic racism and structural discrimination, and medical mistrust, in the health care system experienced by Black women. Some literature concluded institutionalized White socioeconomic resources, discrimination, and racialized framing from centuries of slavery, segregation, and contemporary

White oppression severely limited and restricted access for many Americans of color to adequate socioeconomic resources and health care (Bailey et al., 2017; Castle et al., 2018; Hall et al., 2015). The effects these factors may have on Black women's participation in health practices and programs warrant more investigation and direct study.

Findings on the understanding of Black women's skepticism of medical providers and systems reinforced and expanded our view of the importance of addressing these trust issues in future HIV prevention efforts with this population. This long history will require that critical conversations about race and health take place to begin breaking deeply ingrained cycles of discrimination. Future HIV health practices and programs could benefit from careful attention to interpersonal relationships within the health care system that integrate components of building positive bidirectional communication, restoring trust, and peer education interventions among Black women.

HIV practices and programs have the potential to be accepted by Black women living in low-income housing; however, identifying trusted individuals or gatekeepers in the communities where women live will also be essential in linking women in the community to the needed health care clinics, programs, information, and other resources. A preference for HIV-related messaging and programming to be delivered by community members, as opposed to clinicians, and peer education interventions are strongly recommended.

Disclosures

The authors report no real or perceived vested interests related to this article that could be construed as a conflict of interest.

Key Considerations

- Identifying trusted individuals or gatekeepers in the communities where women live is essential to linking women in the community to HIV prevention and treatment services.
- HIV health practices and programs could benefit from careful attention to interpersonal relationships and communication in the clinical encounter with Black women.
- HIV prevention and treatment interventions that integrate components of building positive bidirectional communication, restoring trust, and peer education interventions among Black women are strongly recommended.

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