



## **African American Adults' Experiences with the Health Care System: In Their Own Words.**

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### **Abstract**

African Americans suffer a disproportionate burden of death and illness from a number of different chronic diseases. Inequalities in health care practices and poor patient and provider communication between African American patients and health care professionals contribute to these disparities. We describe findings from focus groups with 79 urban African Americans in which the participants discussed their interactions with the healthcare system as well as beliefs and opinions of the healthcare system and professionals. Analysis revealed five major themes: (1) historical and contextual foundations; (2) interpersonal experiences with physicians and other health care workers; (3) discrimination; (4) trust, opinions and attitudes, and (5) improving health care experiences. These findings indicate that perceptions of discrimination and racism were prevalent among African Americans in this study, and that the expectation of a negative interaction is a barrier to seeking care. Authors discuss prevention and public health implications of these findings and make recommendations for health care practitioners.

Key Words: African Americans, health disparities, discrimination, focus groups

It is well documented that there are racial differences in the incidence, morbidity and mortality rates for many diseases. African Americans have higher incidence and death rates due to cancer than Whites, Hispanics and Asian/Pacific Islanders; these disparities are found in incidence rates for

prostate, colon and rectal cancers and for breast cancer mortality.<sup>1-3</sup> African Americans also have higher rates of hypertension,<sup>4</sup> diabetes<sup>5</sup> and coronary heart disease.<sup>6</sup> Eliminating these and other health disparities is a public health priority. In Healthy People 2010, eliminating health disparities was one of two overarching goals.<sup>7-9</sup>

A number of factors appear to contribute to these racial disparities including higher representation of minorities in lower socioeconomic groups,<sup>10</sup> environmental factors such as access to care and living in dangerous surroundings<sup>11-13</sup> and cultural values and norms.<sup>12-14</sup> Research has also indicated that discriminatory practices in the healthcare system may contribute to disparities.<sup>15, 16</sup> To help understand how interaction with the health care system might contribute to health disparities, the present study describes the experiences of African American adults and suggests practical approaches that could improve their health care experience.

According to the National Healthcare Disparities Report, African Americans still experience discrimination in quality of care and system/physician interaction and communication.<sup>17</sup> For instance, African Americans experience higher rates of infections following routine medical procedures<sup>12, 15, 16</sup> and longer wait times in emergency rooms.<sup>18</sup> Further, African Americans do not receive the same evidence-based treatments as their White counterparts.<sup>16</sup>

Due to a feeling that they are treated poorly by health care providers and not provided needed information<sup>19, 20</sup> or not encouraged to participate in their care, African Americans are less satisfied with their interactions with their providers and the health care system.<sup>12, 15, 16, 18, 21, 22</sup>

Because of historical experimentation such as the Tuskegee Experiment,<sup>23</sup> many African Americans feel that they are misled by their primary providers or researchers.<sup>19, 20, 22, 24, 25</sup> Understandably, these poor interactions with the healthcare system are deterrents for African Americans to seek medical care,<sup>26</sup> contributing to health disparities.

While the study of health disparities and discrimination has increased, very few studies have examined the personal experiences of African Americans. A number of studies have quantified medical mistrust<sup>21, 24, 27-29</sup> and patient satisfaction,<sup>30-33</sup> however only a small number of qualitative studies have analyzed mistrust in the healthcare setting to capture African American experiences in their own words.<sup>20, 25, 34</sup> In one such study, in-depth interviews were carried out with African American women of childbearing age to gain insight on their experiences with access to healthcare and racism within the healthcare system. Researchers found that African American women believe racism is common in the system and that pregnant African American

women often suffer from stereotyping.<sup>20</sup> Other research collected narratives from African American breast cancer survivors and found that there was a lack of understanding of African American women's experiences with breast cancer.<sup>34</sup> Finally African American postal workers were interviewed about their experiences during the 2001 Anthrax Attacks and it was found that the trust in public health authorities had decreased in the population affected by the anthrax.<sup>25</sup> While these research studies provide valuable insight into specific healthcare related experiences and population subgroups they do not provide adequate insight into the every day interaction that African Americans have with the healthcare system.

The goal of this article is to present the subjective experiences of African American men and women, ages 40 years and over about their interactions with the healthcare system and to make practice recommendations for healthcare providers based on thematic analyses of these data. The present study examines African Americans' interactions with the healthcare system, allowing a broader application of the findings than previously found in the literature. Examining health care interactions in the words of the African Americans who have experienced them allows researchers and healthcare workers to better understand minority patients' perceptions and interact more productively with African American adults. Improving this interaction, and thus the experiences of African Americans in the healthcare system, may ultimately help eliminate health disparities that affect African Americans.

## Methods

Gender specific focus group interviews<sup>35,36</sup> were used to capture the experiences of urban African Americans as part of a larger study to increase colorectal cancer screening among African Americans. This study was approved by the Saint Louis University Institutional Review Board (#12796).

## Procedures

All focus groups in this study were moderated by an experienced African American woman and were held in the St. Louis metropolitan area. African American men provided assistance with male focus groups, however no male team members were experienced in conducting groups.

The focus groups lasted roughly 90 minutes, and were carried out between June and October 2004. Eligible participants, African Americans 40 years and older, were recruited from churches, community centers, government facilities and local business, such as drug stores, department stores, salons and a thrift store.

Three approaches were used to recruit participants using a convenience sampling approach. First, the research staff visited each of these locations to personally invite community members to participate. Second, local community members working with the research team identified potential participants who were then contacted by the project staff. Lastly, flyers were posted at these community venues encouraging interested and eligible adults to contact the project staff. Eligible participants: (1) identified themselves as African American/Black; (2) were 40 years of age or older; (3) lived in the St. Louis area; (4) were born in the United States; and (5) had never had colorectal cancer.

Focus groups were carried out in churches, libraries, a University conference room, and the Neighborhood Voice, a mobile van used for research activities. The focus groups were part of a larger study that aimed to evaluate written materials about colorectal cancer prevention, a large number of focus groups were required to reach saturation of the ideas related to the design and content of the materials, which were different for men and women. Focus groups of men (n=12 groups) and women (n=8 groups) were held separately, and included 3 to 8 participants each. A total of 79 participants (43 men, 36 women) were included in the study.

Participants had a mean age of 50 and a majority of participants (80%) had not obtained a college degree. The largest proportion of participants had a household income of less than \$10,000 (40%), with over 70% having a household income below \$30,000. Focus groups were audio recorded and professionally transcribed.

### **Instrument**

The objectives of the focus groups were to examine general healthcare interactions, health information seeking and cancer beliefs with the goal of creating health communication materials to encourage African Americans to get screened for colorectal cancer and undertake preventive behaviors such as eating more fruits and vegetables. In order to create an atmosphere where participants would be comfortable talking about cancer, the script started out asking general questions about health and experiences with health care. Therefore, the moderator guide included items such as: "Tell me about the healthcare you have received?" and "Tell me about your interactions with people in the healthcare system." The moderator then moved on to talk about cancer beliefs and care. Focus groups were carried out at different stages in the project. The specific questions may have differed depending on the stage of the focus groups, however the general experience questions were

consistent throughout all interviews. Participants were asked broad, open-ended questions and encouraged to include personal stories or anecdotes regardless of whether they perceived those experiences as positive or negative.

### **Coding and Analysis**

An interdisciplinary team of researchers from public health, psychology and anthropology developed the coding guides. We used a consensus coding procedure.<sup>37,38</sup> Eight researchers worked in various three-person coding and analysis teams. Each member of a team coded the focus group transcripts individually, identifying text units that described interactions with the healthcare system, anecdotes about live events, class, disparities, race, trust, distrust, or reason for disparities. Coders then met with other members of their team to reach a consensus on the codes. Each code was discussed during a consensus meeting, so no code was included in the final analysis that had not been agreed upon by all coders. If there was difficulty reaching a coding decision within the group, the project Principal Investigator (VST) made the final decision.

Transcripts were downloaded into Atlas Ti<sup>R39</sup> and after consensus coding was complete, agreed upon codes were entered into the Atlas transcript file. Text units were then grouped by codes and all groupings were analyzed for themes. Participant comments were included in this study when they were coded with a healthcare interaction code as well as at least one of the following codes: anecdotes, class, disparities, race, trust, distrust, or reason for disparities. All of the text blocks meeting these coding criteria were printed from Atlas Ti and reviewed independently by two members of the research team to verify that the text section should be included in this analysis. Researchers then met to reach consensus on which sections should be included and then analyzed the text for themes.

### **Results**

Data analyses revealed five major themes related to personal interactions with the healthcare system: (1) historical and contextual foundations; (2) interpersonal experiences with physicians and other health care workers; (3) discrimination; (4) trust, opinions and attitudes, and (5) improving interactions with the health care system. These major themes are discussed below and quotations from focus group participants (in italics) are used to illustrate these themes.

## Historical and contextual foundations

The generation of African Americans over 40 remembers the atrocities of the past. *"We've got a legacy of not trusting the medical establishment for a lot of reasons."* Participants were aware that those who came before them were often mistreated by the health care system and given inadequate care. Many feel they have had some of the same negative experiences themselves. When talking about her grandparents one participant said, *"they were sometimes used for certain studies, and they didn't know they were being used."*

Many participants used the term "guinea pigs" to describe how African Americans have historically been treated. *"We know we've been guinea pigs on a lot of studies, especially if you've been in jail."* For some participants, experimentation was not just a concern of the past; participants believed African Americans were still the subjects of unwanted experiments, and felt vulnerable to such threats. *"There have been studies on us ever since they brought us here, so they gonna keep on doing studies until we leave on our own or they ship us back."* Another participant reported, *"You just got to sit back and take it."* This group of African American participants remembered specific instances of experimentation.

Past travesties were a part of their present reality, and fostered a very real sense of distrust with the medical community. *"They use black people as guinea pigs...it has happened. It's real."* These beliefs about experimentation affect trust in the medical system, and may discourage African Americans from seeking much-needed healthcare, and specifically preventative care. *"Because of the Tuskegee study, a lot of other things, we just basically don't go to the doctor until something hurts."*

## Interpersonal experiences with physicians and other health care workers

Participants from the focus groups described a range of experiences interacting with the healthcare system, many of which were perceived as negative events. Participants felt at times that their safety was in jeopardy due to physician incompetence, reckless prescription of medicine, or purposefully inadequate or dangerous treatment. One participant spoke about her experience with a primary care physician:

*I don't think he knew what he was talking about because he didn't examine me or nothing. And when I came back in there he got three pills in a little jar, sitting for me...I threw them away because I don't think he knew what he was talking about because he ain't listen to my heart or my blood pressure or nothing.*

A number of other participants displayed frustration and doubt about what they perceived as physician incompetence. It was also not uncommon for participants to see themselves in worse shape after they had seen a physician than before they went in. *"He cut me worse...and I couldn't walk with this cut, and I walked into the hospital with the other cut."* Another participant described the treatment that a loved one received, *"My son-in-law has lung disease and they gave him this stuff, but it makes everything worse. Like it's making him bleed...or it's making him have lesions on his body."* For some participants doctors were perceived not as providing treatment, but rather experimenting on African Americans. Participants felt that doctors really did not know what they were doing or how to cure someone. *"Doctors, they're just experimenting on you. Medical doctors, they don't know exactly if it's going to cure you."* Physicians and other healthcare providers were often seen as withholding information from patients, maybe even lying to them. *"I'd been having stomach problems; they cut me all open. They won't even let me see the x-rays or nothing. I want to know what's going on."*

Another issue for participants involved medication. One participant was concerned about being given medication that didn't work *"They give me medicine and say it's going to do one thing. And it doesn't do, it don't do what they say."* Participants also thought their physicians at times could be reckless with their prescriptions for medication, mostly because participants perceived that doctors did not perform adequate exams before the medicine was prescribed. One participant said her physician renewed her medication even though she hadn't seen him in two years. *"Any doctor should know that you don't give no [medication] for two and a half years without checking them."* The relationship of the physician with drug companies was a concern of one participant; feeling he or she was given dangerous drugs because the physician had a relationship with the manufacturers.

*He gave me this prescription. I think it was (name of medication). And I heard on TV where (name of medication) is causing all these problems and they were having a lawsuit. So I think sometimes doctors will push certain medications...I think they help out the prescription industry.*

Many of the study participants experienced what they perceived as rudeness or stereotyping from healthcare providers or other healthcare workers. Poor bedside manner and communication skills were reported as common experiences among participants. Participants gave examples of their experiences including:

*And the assumption that we (African Americans) are all alike. Sometimes I've had doctors, in hospitals would assume that we are all the same, we all eat the same. We all have the same bad habits and that's not true.*

Participants reported that they often had no choice but to interact with physicians who were unkind. *"You know you're spending all of this money and they want to treat you like... he didn't know how to talk to you. He didn't make me feel like he was concerned at all. And I thought that was horrible."* Perceived disinterest was also a frustration of many participants, as they felt that healthcare professionals were not concerned or interested in what they had to say. *"That's what I don't like, you know. He's not concerned about what's bothering me. As long as I come and visit, Medicaid is going to pay him."* Participants felt that some of this disinterest was also related to physicians treating them only to be paid or obtain other financial benefits. *"I don't know if he took me because it was a write off for him, because some doctors do that."*

### **Discrimination**

Both racial and economic discrimination were regularly discussed by African Americans when discussing their experiences with the health care system. A number of participants reported waiting long periods of time for service, and attributed this to their race or economic position.

*These guys go in front of me with a broken finger... I sat there like four hours and I didn't get in. And they said something about insurance... so I had to just sit there and wait in the waiting room.*

Some participants felt that they were treated poorly not because they were African Americans, but because they didn't have any insurance or had inadequate coverage. *"What affects... our health these days is that we don't have adequate medical coverage. You can go to the doctor, you can get waited on after 10 hours."* Another participant reported, *"If you go to the hospital, you're poor, they're not going to turn attention because it costs the hospital."* One participant said he had a vastly different experience in the health care system when he was insured than when he was without insurance.

*I didn't have Medicaid one time and I went to the doctor... I sat there and I waited and waited because I didn't have no insurance. Finally I got seen but they didn't give me much attention... when I got Medicaid, I'm right in there, you know. They seen me, asked questions, this and that.*



Sometimes participants spoke of how African Americans as whole were given poor care because of their race: *“I just feel that White people have always been able to get the best of care. Blacks have more cancer because we’re not ... getting the best of care or the money to go to the doctors.”*

### **Trust, opinions and attitudes**

A central theme in these data is that many African American adults do not completely trust their health care providers. Their personal experiences, in addition to what they have learned from others’ experiences, have shaped their opinions about the health care system. In general, African American adults in this study population were fearful of doctors, not because doctors may be delivering bad news or because of the cost of health care, but because they are skeptical, even suspicious, of the quality of care they will receive. For this reason, participants felt the need to become advocates for their own health care:

*We have been in(ter)jected with all different kinds of medications and chemicals in our body... As time go on we get sicker and sicker. When you go to the doctor you be very careful and you ask them what kind of shot are they giving you.*

### **Improving interaction with the healthcare system**

Many participants felt that because they couldn’t trust the health care system to take care of them, they had to take control of their own health status, Participants also wanted to have more control over their interactions with the healthcare system.

*I know that when I used to go to the doctor I’d go with a list. And when he would look at me and the first thing that came out of his mouth was, ‘When did you get a medical degree’ I said that I know my body and I have been living with it all for these 48 years. Excuse me, but you don’t know my body.*

For some participants, taking control meant changing doctors. For example, one participant stated,

*One medication and I was taking it for high blood pressure, and I started itching... he (the doctor) said, ‘well, I didn’t want to tell you that was a side effect of this medication and see if it worked’... that’s when I changed doctors.*

Participants felt that physicians who build good rapport with patients provide better experiences for their patients. *"I like my doctor. She's always talking about trips, where she's going. I feel like she is like a family member... It's kind of like rapport. It's not like you're just another statistic."*

## Discussion

Consistent with previous reports in the literature,<sup>40</sup> our findings underscore that the negative experiences that urban African Americans have had interacting with the health care system are only partially due to access and economic issues. Perceptions of discrimination and racism are prevalent, and the decisions people make are highly related to their past experiences. In this study, these past experiences often acted as barriers for participants seeking health care. According to some participants, they didn't seek healthcare unless it was absolutely necessary. If African American adults do not seek care for an acute problem because they anticipate a negative interaction with the health care system, using preventive care may be even less likely. Improving the experiences that African Americans have when interacting with the healthcare system may not only lead to better health outcomes in the short term, but more effective prevention efforts as well.

African Americans have been on the receiving end of well-publicized health care abuses, and have many reasons to be distrustful of the healthcare system. Health care providers, public health researchers and policy makers must broaden their focus and deal with issues such as discrimination, mistrust, stereotyping, and minorities being provided inadequate healthcare. Specifically, it is important that health care professionals understand the need for building trust with their patients. Simply put, participants in this study wanted to be treated as individuals, respected, given adequate information, and be actively engaged by their healthcare providers. Participants often felt they were stereotyped by those in the system, ignored or treated by uncaring providers, and that providers often didn't take the time to talk with them.

In a time when many physicians and health care providers are overextended, it may be difficult to build relationships with patients. Rapport and trust are developed over time, which is often not available in busy clinical practices. Although a recent review has shown that physician centered interventions can improve the adoption of preventive services by African Americans,<sup>41</sup> physicians report that they are not trained to interact with patients in culturally appropriate ways.<sup>42</sup> Programs that educate physicians about health disparities and the importance of culturally appropriate care

may show promise, and the development of cultural competencies for clinical training programs may enhance the ability of practitioners to address these health disparities.<sup>43</sup>

The use of qualitative methods allowed us to gain an in-depth understanding of the individual experiences of the participants. However, this methodology has limitations that should be acknowledged, particularly lack of representativeness. Participants were all volunteers and it is difficult to know how they differ from individuals who did not volunteer to participate. The provision of a monetary incentive may have also resulted in a larger proportion of low-income participants than is present in the larger African American population. Because the parent study focused on colorectal cancer, this sample focused on older African Americans. Finally, all groups were moderated by an African American woman, which may have influenced the responses of African American men in ways that are not addressed in this paper. While the sample may not be representative of African American adults in St. Louis because convenience sampling was used, the findings are important for those working in health care and provide insight about how urban African American adults perceive their healthcare experiences.

## Recommendations and Conclusions

This work supports the action steps proposed by Adderley-Kelly and Green for researchers working with disadvantaged and/or ethnic populations.<sup>44</sup> Adderley-Kelly and Green recommend that those working with minority groups work hard to establish a trusting relationship by engaging in a conversation with patients, listening to patients, being honest about knowledge or treatment limitations, showing all those involved respect, and treating people as individuals.

In order to fully address issues like those raised by study participants, system wide changes in healthcare may be needed, including policy, training and fiscal changes. Findings from this study suggest several smaller scale changes that could be adopted by individual health care providers now to enhance interactions with low-income African American adults:

1. ***Historical and contextual foundations.*** When working with African Americans, a population with a long and clear history of discrimination at the hands of medical, scientific and social systems, it is important to know and understand the history. Health care providers should make an effort to learn about Tuskegee, and use what they have learned to avoid any interactions that could be perceived as discriminatory. While younger practitioners may

dismiss the Tuskegee experience as long ago, it is very real in the mind of African Americans as study participants specifically named the experiments in their comments.

**2. Discrimination.** It may be important to discuss issues such as long wait times with patients. Medical care professionals should be honest about how long patients may need to wait to get care. Further, a clinic or hospital representative should take sufficient time to talk with patients about insurance issues. Health care providers need to realize that even health care system processes that are generally frustrating or inefficient for all patients (e.g., waiting time, paper work) may be perceived as discriminatory by those with a history of unsatisfying health care interactions.

**3. Trust.** Building trust is a long process. Providers can begin this process by answering questions, explaining the need for certain medications and possible side effects, providing accurate and understandable medical information, and building rapport. Clearly, providers should demonstrate an interest in their patients, encourage their patients to ask questions, and should answer all questions, listen to patient concerns and even share personal stories or experiences that might be relevant to the patient and his or her experience. Providers learn to follow the patient's lead as they attempt to establish rapport and should be willing to address the limits of their knowledge and certainty, as this will promote discussion of patients concerns and doubts. As this trusting relationship is cultivated, the experiences of the patients will improve which may ultimately contribute to a reduction in health disparities.

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