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## Exploring Four Barriers Experienced by African Americans in Healthcare: Perceived Discrimination, Medical Mistrust, Race Discordance, and Poor Communication

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Exploring Four Barriers Experienced by African Americans in Healthcare:  
Perceived Discrimination, Medical Mistrust, Race Discordance, and  
Poor Communication

by

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requirements for the degree of

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## Abstract

For many health conditions, African Americans bear a disproportionate burden of disease, injury, death, and disability compared to European Americans. African Americans also use health services less frequently than do European Americans and this underuse of services contributes to health disparities in the United States. Studies have shown that some disparities are present not as a result of poor access to care, but, to a certain extent, as a result of the experiences patients have at their doctors' offices. It is, therefore, essential to understand African American patients' perspectives and experiences with healthcare providers. Past studies have shown that four barriers affect the quality of patient-provider relationships for African Americans: perceived discrimination, medical mistrust, race discordance, and poor communication. The studies, however, have not looked at how these barriers manifest when African Americans speak about their perspectives and experiences with health care providers. This project was a secondary data analysis of qualitative data provided by adult African American community members from Portland, Oregon with diabetes or hypertension or both, each of whom participated in one of 10 focus groups. The focus groups were conducted as part of a study that applied community based participatory research (CBPR) principles to understand patients' experiences with their doctors. Using a deductive approach, this analysis enhanced the understanding of how the barriers play a role in patient-provider relationships. Further, the analysis showed how the barriers are interrelated. In learning African American patients' experiences and perspectives on these four key barriers, the investigator proposes recommendations for healthcare providers as to how they can best deliver quality care for African Americans.

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### **Introduction**

Racial and ethnic health disparities create persistent problems for African Americans in the United States (CDC, 2011). For example, in 2003, the difference in life expectancy at birth between African Americans and European Americans remained substantial at 6.3 years for men and 4.5 years for women (Harper et al., 2007). African Americans continue to show higher prevalence than the majority population for diabetes, hypertension, and cardiovascular disease (Office of Minority Health, 2009). Although African Americans have higher morbidity and mortality rates, they are less likely to use healthcare. Even when they do use healthcare services, they are less likely to adhere to medication or utilize the same healthcare service again than European Americans (Diala et al., 2000; Traylor et al., 2010).

Underutilization of health services is an important factor that contributes to the existing health disparities (Hass et al., 2004; Weinick & Krauss, 2000). Although service use is affected by many factors such as socioeconomic status, access to care, and health insurance coverage, an important key element to the utilization and continuity of health services is the quality of care itself for ethnic minorities (Zastowny, Roghmann, & Cafferata, 1998). African Americans have been shown to receive lower quality of care than their European American counterparts (Mayr et al., 2010; Bach et al., 2004). For example, obese African American patients are less likely to receive counseling about diet and exercise than their European American counterparts (Bleich, Simon, & Cooper, 2011). Further, African Americans are less likely to receive many types of medical services and procedures (Egede & Bosworth, 2008). For example, African American women are more likely to die from breast cancer than any other ethnic group (American

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Cancer Society, 2009). However, African American women are less likely than European American women to have breast cancer diagnosed from a mammogram (18% versus 31%) or clinical breast exam (8% versus 21%; Elmore et al., 2005). Many of these problems with quality of care can be explained by the barriers found in the relationship between the minority patient and his or her physician (Scheppers et al., 2006). As Ashton et al. (2003) suggest some disparities appear after the patient gets to the doctor's office.

The patient-provider relationship is an important factor affecting quality care for patients (Meredith et al., 2001; Saha et al., 2003). There is evidence that African Americans have poor relationships with their healthcare providers. African Americans, for example, report less satisfaction with the quality of care and are more likely to report communication problems with physicians than are European Americans (Collins et al., 2002). African Americans are shown to be less active in patient-physician partnerships (Cooper et al., 2006) and report lower quality interactions with their physicians (Cooper-Patrick et al., 1999).

Why do African Americans report unfavorable views toward health care services? Prior research suggests four reasons: perceived discrimination (Casagrande et al., 2007), medical mistrust (Benkert et al., 2006), race discordance (Saha et al., 1999; LaVeist & Nuru-Jeter, 2002), and poor communication (Rim et al., 2007) between patient and provider. However, no studies have yet examined these four barriers together and how they might be interrelated to one another. Further examination of these four factors can help researchers understand how they affect the patients' healthcare experiences. African American patients' reports of their past experiences with, and perceptions of, healthcare institutions and healthcare providers may yield valuable insight into these four factors.

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In this study, I explored whether, and in what ways, these four factors appeared in the focus group discussions of African American men and women. Prior studies have shown that these barriers negatively affect patient-provider relationships, but few have captured how patients actually speak about these barriers. By using a deductive (top-down) approach in this study, moving from *a priori* concepts to exploration of those concepts in the discussion narratives, I have been able to explicate each of these concepts in patients' own words, and to demonstrate the intersectionality that exists among these concepts.

To fully understand the four concepts, it is important to first understand how *African American*, as an ethnicity, is defined in this study. *Ethnicity* is defined in terms of the commonality of culture and tradition that a group of individuals share in a social context. Markus (2008) draws from the literature on social identity to offer a more comprehensive definition:

Ethnicity is a dynamic set of historically derived and institutionalized ideas and practices that (1) allows people to identify or to be identified with groupings of people on the basis of presumed (and usually claimed) commonalities including language, history, nation or region of origin, customs, ways of being, religion, names, physical appearance, and/or genealogy or ancestry; (2) can be a source of meaning, action, and identity; and (3) confers a sense of belonging, pride, and motivation. (p. 654)

At a conceptual level, the often muddled uses of *race*, *ethnicity* and *culture* in the social sciences echo the uses of the terms *sex* and *gender*. Although, at first, these may seem to be different matters they bear conceptual parallels. For example, feminist scholarship on sex and gender argues that gender serves as both a *subject variable* – an enduring characteristic of a person or persons – and a *stimulus variable* – a perceived characteristic

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which is mainly of interest because of the responses of others who respond to that characteristic (Shields & Dicicco, 2011). The difficulty of the concept *race* is its misuse as a supposed subject variable. The difficulty of the concept *culture* is its nature as a subject variable, when the phenomena of interest require a construct which is in part subject variable and in part stimulus variable. Therefore in this study, have examined the experiences and perspectives of individuals who hold in common a self-identified African American *ethnicity*. I did not explore cultural or other forms of diversity such as socioeconomic status within the African American group. Rather I construed the social category *African Americans* as a group of people with commonalities including language, history, customs, and ancestry. I treated ethnicity as a construct which is simultaneously a subject variable and a stimulus variable.

Studies have shown that race and ethnicity shape psychological experience (Cuddy, Fiske, & Glick, 2007; Plaut & Markus, 2005, Markus, 2008). Further, ethnic and racial identities have been shown to be important predictor of attitudes and behaviors (Ramirez-Valles, Zimmerman & Newcomb, 1998; Kaplan et al., 2004). Many of these behaviors and attitudes are shaped by how the “other” sees the members of a given group -- their status, in other words, as stimuli or attitudinal targets. Simplified conceptions of a particular social group, held by others who are not in that group, can have negative effects on target group members (Steele & Aronson, 1995). Stereotypes are beliefs, and prejudice is an attitude; however, stereotyping can provide cognitive content which facilitates or perpetrates prejudice and discrimination (Link & Phelan, 2001; Sekaquaptewa & Thompson, 2003). Such prejudice and discrimination do not always have to be overt to affect the attitudes and behaviors of target group members. As Steele

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and Aronson (1995) have compellingly demonstrated, the experience of anxiety or concern in a situation wherein individuals have the potential to confirm a negative stereotype about their social group can affect individuals' performance. This is particularly pertinent when the target individual believes he or she is being mistreated based on the negative stereotype.

Such beliefs, particularly in the healthcare system, are likely to have multiple causes, including experiences of discrimination and disrespectful treatment, and including more subtle perceptions of being perceived stereotypically by healthcare professionals (Blanchard & Lurie, 2004; Van Houtven et al., 2005). Studies have shown that healthcare providers hold conscious and unconscious negative stereotypes of minority patients, tending to view them as less educated and less likely to be adherent than their European American counterparts (van Ryn & Burke, 2000).

How does the subjective experience of discrimination affect the health of target persons? The model by Pascoe and Richman (2009), shown in Figure 1, is based on their meta-analysis of research on discrimination and health. This model illustrates three pathways through which perceived discriminatory experiences may affect mental and physical health. First, perceptions of discrimination could have a direct effect on health (path a); for example, perceived discrimination has been shown to be associated with psychological distress (Williams et al., 2008), depression symptoms (Bogart et al., 2011), and overall poor mental and physical health (Penner et al., 2009). As a second possibility, the relationship can be partially *mediated* through stress responses to a discriminatory event (paths b and c). For example, routine discrimination can become a chronic stressor that may erode an individual's protective resources and thereby increase vulnerability to

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physical illness (Gee, Spencer, Chen, & Takeuchi, 2007). Pascoe and Richman (2009) argued that if an individual perceives discrimination on a regular basis, stress responses are activated more often, potentially leading to a frequently negative emotional state. Third, a mediating mechanism, tested by Pascoe and Richman in their meta-analysis, the role of health risk behaviors (path d) emerge as possible coping mechanisms when discrimination is experienced. For example, an African American who believes she has received unfair treatment by a physician may be less likely to adhere to the physician's recommended treatment plan or to return for follow-up visits. As represented by path e, these consequences can in turn have detrimental effects on psychological and physical health.

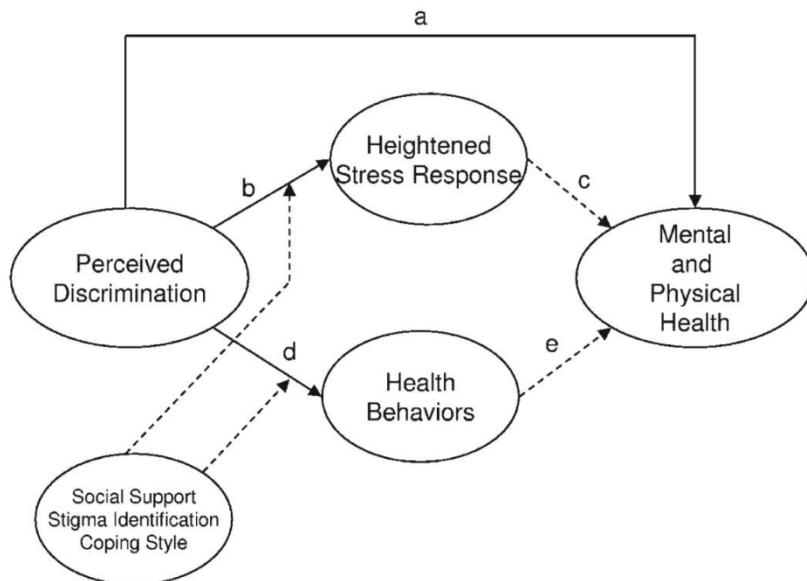


Figure 1. Pathways by which perceived discrimination influences health outcomes (Pascoe & Richman, 2009). Solid lines indicate analyzed pathways; dashed lines represent pathways hypothesized by past research.

Historically, African Americans have experienced discrimination in the United States. African Americans are more likely to perceive racism and discrimination than are

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European Americans (Robert Wood Johnson Foundation, 2005). For example, a study of 4,157 randomly selected U.S. adults comparing perceptions of health care among a variety of different racial and ethnic groups found that members of many ethnic minority groups view their health care situations differently and, often, more negatively than European Americans. Particularly, African Americans perceived discrimination in receiving health care, and many felt that they would not receive the best care if they were sick (Blendon et al., 2007). Most differences remained when socioeconomic characteristics were controlled for analytically. Adegbembo (2006) similarly found that African Americans perceived more racism in the healthcare system than do European Americans. Studies have further demonstrated that perceived discrimination contributes to differences in patient behavior. For example, in a study of randomly selected community members, Van Houtven et al. (2005) found that perceived discrimination was associated with the person delaying medical tests and treatment. Reports of perceived discrimination were also linked to lower rates of participation in preventive health services (Blanchard & Lurie, 2004).

Perceived discrimination has been shown to be negatively associated with physical and psychological health as well (Williams & Mohammed, 2009; Burgess et al., 2008; Brondolo et al., 2009a, Brondolo et al., 2009b). Reports of perceived discrimination from African American patients are associated with lower likelihoods of quality treatment (Napoles-Springer et al., 2005; Hoyo et al., 2005; Casagrande et al., 2007; Fowler-Brown et al., 2006; Facione and Facione, 2007). For example, African Americans who perceive discrimination report lower medication adherence, provide lower patient ratings of visit informativeness, and underuse healthcare services compared

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to European Americans (Casagrande et al., 2007; Hausmann et al., 2011; Burgess et al., 2008). Before these negative perceptions can be addressed, research must uncover some of the factors that influence them. One factor that has been shown to be a major influence in African American's perception and experience is medical mistrust.

### **Medical mistrust**

Although other researchers (Thompson et al., 2003; Hammond et al., 2010) have not used the term *mistrust* as a cultural phenomenon, they indicate their awareness of the prevalence of mistrust toward healthcare found among African Americans. Therefore, I use *medical mistrust* as a main term encompassing a range of terms (e.g., cultural mistrust and medical distrust) that are found in studies pertaining to African Americans in the healthcare system. Terrell and Terrell (1981) defined *cultural mistrust* as an inclination among Blacks to mistrust Whites, with mistrust being most evident in interpersonal and social relations. Terrell and Terrell describe this as a cultural phenomenon that exists for African Americans, having developed a reluctance to trust majority ethnic group members due to historical and contemporary experiences with racism and oppression. As Whaley (2001) mentions, this is not to be misconstrued as clinical paranoia, in which the distrusting persons see themselves as uniquely targeted, and thus may be seen as psychopathological; rather, cultural mistrust is a response style from African Americans based on historical and contemporary experiences with racism and oppression.

Scholars such as Whaley (2001) and Townes (2009) have linked long time oppression, social disadvantage, and historical events that involved African Americans receiving unfair treatment to the present mistrust that many African Americans hold

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towards the healthcare system. African American men have been shown to choose not go to the doctor because of their distrust (Hammond et al., 2010). This deep mistrust towards healthcare organizations and health professionals has been linked to dissatisfaction, noncompliance, and underuse of healthcare services (Hammond, 2010; Hall et al., 2001; LaVeist et al., 2000; LaVeist et al., 2009). African Americans who hold mistrust tend to have more negative views and expectations of their health providers than do other African Americans who do not hold mistrust (Thompson, Bazile, & Akbar, 2004). For example, a study of 214 African American men diagnosed with HIV examined whether a specific form of medical mistrust – HIV conspiracy beliefs (e.g., "HIV is genocide against African Americans") – was associated with antiretroviral treatment nonadherence among African American men with HIV (Bogart et al., 2010). Confirmatory factor analysis revealed two distinct conspiracy belief subscales: genocidal beliefs (e.g., "HIV is human-made") and treatment-related beliefs (e.g., "People who take antiretroviral treatments are human guinea pigs for the government"). Both subscales were related to antiretroviral treatment nonadherence, thus showing that medical mistrust may contribute to health disparities by discouraging appropriate treatment behavior. Nicolaidis et al. (2010) similarly reported that African American women with histories of depression and/or partner violence viewed the healthcare system as racially biased and untrustworthy as well. In that report, an African American woman illustrated the lack of trust toward European Americans, "You know, it's in our culture; you don't go tell White people nothing." This lack of trust towards the dominant culture reflects that mistrust need not be based on personal past experience (e.g., participation in the Tuskegee study), but can be learned through members of one's ingroup (e.g., ingroup knowledge of the Tuskegee

study). Consequently, learned distrust may become part of the schematic framework with which one sees, and responds to, the social world.

### Race discordance

LaVeist and Nuru-Jeter (2002) argue that racial and ethnic disparities in the use of health services, quality of care, and health status would be reduced by increasing the number of minority health care providers in the U.S. This is based on the notion that race discordance between provider and patient contributes to disparities in health. In light of the earlier discussion on the concepts of race, culture, and ethnicity, it is important to mention that in the existing literature, race concordance is defined as patients having the same racial and ethnic background as their healthcare provider; therefore I have used the term *race* while considering it, like ethnicity, both a stimulus variable and a subject variable.

According to Malat et al. (2009), African American patients are less likely than European American patients to see a race concordant doctor. It is then assumed that if an African American patient has a race concordant doctor, he or she will most likely use health services more often and rate those services favorably. Saha et al. (1999) found that African Americans patients were more likely to rate a race concordant physician more favorably and were more likely to report receiving preventive care and medical care than patients with race discordant doctors. Similarly, Cooper-Patrick et al. (1999) found that African Americans patients who had race concordant physicians rated their visits as significantly more participatory than patients who had race discordant physicians. These findings suggest that the patient's perception of the physician's ethnic background may affect the quality of care; the same may be said of the physician's perception of the

patient's ethnic background, as well. van Ryn and Burke (2000) found that European American physicians rated African American patients as less intelligent, less compliant, and more likely to engage in risky health behaviors than other patients. van Ryn and Burke suggested that such attitudes may be perceived by patients via nonverbal cues or verbal tone or inflections, consequently influencing the patient to negatively respond to the physician's behavior. In other words, in the case of a European American physician, the European American physician's behavior can lead to a poor interaction with the African American patient. This in turn leads the African American to prefer a race concordant doctor (Chen et al., 2005).

Studies have shown that African Americans who had the ability to choose their own doctor were significantly more likely to be race concordant with their physician compared with respondents that lacked choice in their physician (LaVeist & Nuru-Jeter, 2002; Saha et al., 2000). Patients are more likely to trust and feel more comfort with physicians of the same ethnic background (Street et al., 2008). LaVeist and Nuru-Jeter (2002) suggest that the source of such trust among patients may be an intrinsic sense of connection to members of their own racial/ethnic group, with the expectation that a physician of their same racial or ethnic group will exercise a greater sense of agency with regard to patient care. This may explain why African Americans report a more positive attitude toward race concordant doctors than race discordant doctors and believe race concordant doctors understand their health problems (Malat et al., 2009; Saha et al., 1999).

Race is not the only variable on which physicians and patients may be similar or different. Gender, age, and language or dialect are further variables which merit study.

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Even so, the mentioned studies have shown that race concordance plays an important role in African Americans' use of services and communication with their physicians.

Qualitative investigations may help to uncover why race concordance is valued by African American patients, while also exploring the complexities of this phenomenon.

Such an understanding may help agents within the healthcare system to determine where greater efforts should be placed, for example, increasing the number of African American physicians and/or improving the ability of how physicians interact with patients who are not of their own ethnic background.

### **Poor communication**

Effective communication between patients and providers is essential to achieving positive health outcomes. It is also essential in the maintenance of positive patient relationships among patients in general (Piette et al., 2003; Travaline, Ruchinskas & D'Alonzo; 2005). A successful relationship contributes to the patient's continuance of care and adherence to prescriptions. Poor communication, conversely, can become a cause for the low use of services for ethnic minorities, particularly African Americans. Patient ethnic background is an often overlooked but important variable within doctor-patient communication studies (Schouten & Meeuwesen., 2006). It is important to examine how a patient's ethnic or cultural background affects communication with healthcare providers (Schouten et al., 2007). In turn, a doctor's understanding of the patient's ethnic background can in some cases benefit the communication (Schouten et al., 2007).

Studies have shown, however, that this level of understanding is largely missing. For example, Gordon et al. (2006) found that African American patients who were

diagnosed with pulmonary nodules or lung cancer received less information from their doctors and were less active participants than European American patients. They also found that African American patients engaged in fewer communication behaviors (i.e. asking questions, expressing concerns, assertions) that usually bring forth more information from doctors. These findings imply that African American patients are less active in the exchange of information and involvement in decision making, thus decreasing the chance of obtaining a positive health outcome (Stewart, 1995). This lack of involvement needs further understanding; if it is, in part, a response to the physician's communicative behavior this would have implications for the training of physicians.

Studies have shown that African American patients report that doctors do not spend enough time with them, do not respect their intelligence, and do not provide sufficient explanations (Gordon et al., 2006; van Ryn and Burke, 2000). Furthermore, studies have found that the doctor–patient interaction in interethnic consultations is rated by third-party observers as less friendly and warm than the doctor–patient interaction in consultations between persons of the same ethnic background (Schouten et al., 2006). As a consequence, patient non-adherence and dissatisfaction become more likely to occur.

Thus, the relationship between patient and provider is a key place to look to improve our understanding of patients' experiences of disparities in care and to identify possible steps for intervention. This study asked:

**Research Question 1:** To what extent do the four concepts of perceived discrimination, poor communication, medical mistrust, and race discordance manifest when patients speak about their experiences with, and their perspectives on, healthcare providers?

**Research Question 2:** To what extent do patient narratives about their experiences with, and their perspectives on, healthcare providers help us to understand the four concepts of perceived discrimination, poor communication, medical mistrust, and race discordance? A deeper understanding of these four concepts may contribute to a fuller picture of African Americans' experiences with the healthcare system.

### **Method**

This secondary data analysis is based on an original study which aimed to determine what constitutes a good or bad relationship from the perspective of patients, across three broad ethnic groups (African American, Latino/Latina, European American). The study, known as Project EQUALED (Exploring the Quality of African American and Latino/Latina Experiences with Doctors), was supported by the Robert Wood Johnson Foundation with Somnath Saha as Principal Investigator and with Kerth O'Brien and Teresa Gipson as Co-Principal Investigators.

#### *Community-Based Participatory Research*

In its work with members of the African American community, Project EQUALED employed several principles of community-based participatory research (CBPR). Israel et al. (1998) give an in-depth and widely recognized explanation of CBPR, describing it as a collaborative and equal partnership approach to research that involves community members, community organization representatives, and researchers in all aspects of the research process. Israel and colleagues further state that the partners contribute their expertise and share responsibilities to increase understanding of a certain phenomenon, with the goal of integrating the gained knowledge with action to enhance

the health and well-being of community members (Israel et al., 1998). Although Israel et al. (1998) provided additional principles, the principles which were particularly relevant for this particular study included that CBPR recognizes community as a unit of identity; CBPR promotes a co-learning and empowering process that attends to social inequalities; CBPR addresses health from both positive and ecological perspectives; and CBPR involves a long-term commitment by all partners.

A CBPR approach may be particularly appropriate when the community partners and participants of interest are African Americans. Because, as mentioned earlier, many members of the African American community lack trust towards people of government institutions, this approach enhances trust among potential and actual participants, empowers and provides resources to the participating African American community, and creates a genuine relationship between researcher and community members. To operationalize these CBPR principles, Project EQUALED included a community liaison on the research team and enlisted the guidance of a Community Advisory Board. In recruiting participants the project used community-based recruitment strategies, including attending community events, advertising in community venues, and relying on word-of-mouth dissemination by participants and advisory board members.

**Focus group facilitators and training.** Potential African American focus group facilitators were identified by community advisory board members and other community members. Focus group facilitators attended a one-day, 8-hour training session; the academic members envisioned a pool of potential facilitators from which to draw from, based on availability. The first half of the session was largely didactic and included content on the purpose of focus groups, their advantages and disadvantages as a data

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collection method, and guidelines for appropriate focus group facilitation. In the second half of the training session, the academic members held mock focus group sessions, where trainees practiced asking questions and facilitating discussion. Trainees were given incentives for their time and participation. The academic members chose four African American trainees (two men, two women) to lead the focus groups. All, but one, focus groups were led by the four African American trainees. One focus group was co-moderated by the (European American) project manager and an African American community member.

**Participant recruitment.** The research team posted study flyers in a variety of venues (restaurants, stores, barber and beauty shops, etc.). The research team avoided clinics and hospitals as recruitment sites, because the researchers wanted the sample to be truly community-based, not clinic-based, and because the researchers did not want to oversample from any particular health care facility. Because the enrollment method could have potentially led to few enrollments, a member of the research team went to specific sites and events (e.g., a community walk) and enrolled participants onsite. The researchers asked potential participants to spread the word in their community about this study.

**Focus groups.** The research team conducted focus groups to identify the perspectives of participants, as well as to understand their shared experiences, while accessing the language participants used to think and talk about the study topics. These purposes are consistent with social scientific uses of focus groups (Morgan, 1996; Hughes & DuMont, 1993). The focus groups were held at a community coffee house in inner NE Portland. The researchers formed a total of ten African American focus groups,

five groups of females and five groups of males. The focus groups had between 6 to 10 people in each. During the focus group sessions, one moderator asked the questions and led the discussion, while the other moderator took notes and monitored the discussion to ensure balanced participation. Often moderators traded these roles within a given discussion. With help from the Community Advisory Board, research team members created the focus group guide to learn about people's actual experiences in the healthcare system, particularly their interactions with physicians, as well as their values and preferences regarding doctor-patient interactions. The interviews were semi-structured, allowing the moderators the freedom to probe interesting areas that occurred during the sessions (Smith, 1995). The focus group guide included questions about experiences with most recent visits to the doctor; questions about good experiences with doctors (i.e., actual experiences and what makes a good experience); questions about bad experiences with doctors (actual experiences and what would have made for a better experience); questions of experiences and preferences regarding physician's race/ethnicity and advice to doctors. After each focus group session, the investigators distributed a brief questionnaire asking participants to provide demographic information.

**Transcription.** A freelance transcriptionist transcribed all of the African American focus group dialogue and placed the transcriptions into Microsoft Word documents. Each focus group was given its own file.

### **Data Analysis**

In the original study analyses we used grounded theory to create theme-driven understandings of patient experiences and perspectives for each of the three respective ethnic groups. Although I was not involved in the original data collection I was involved

in the analysis of study data (Cuevas et al., 2011). In this secondary analysis instead of using this same approach to the data I used a deductive approach; that is, I began with the framework of the four concepts to see how the existing codes, based on participants' discussion narratives, conform to the already-developed framework.

I used *NVivo 9 Student*, a qualitative software, to assist me in my analysis of data. I began my analytic process by looking at the existing codes from the original study to look for codes pertaining to the four barriers. I then created a new NVivo file and began to code the text using the four frameworks (i.e., perceived discrimination, medical mistrust, poor communication, race discordance). I organized labels and categories under which the raw data seem to fit. That is, I devised a common system of four main categories (i.e., perceived discrimination, medical mistrust, race discordance, poor communication) and sub-categories across the whole set of 10 focus groups, and used that as a means of searching for and retrieving large segments of labeled data. I decided this approach offered a systematic overview of the scope of the data, to aid finding examples which do not appear in an orderly way in the data, to aid locating conceptual, analytical categories in the data, and to help getting a handle on the data for making comparisons or connections (Ritchie & Lewis, 2003). This method also allows others to replicate the analytic process or review the analytic building blocks to better understand the final results. I also wrote memos -- essentially, these are margin notes -- of the way I interrogated the data, developed categories, and how relationships between categories manifest. I also wrote memos of my own thoughts about the data and future research directions. These memos were formally logged and viewed as part of the interpretative process. Lastly, using *NVivo 9 Student*, I built a hierarchy of categories (tree nodes) to

examine how well the four frameworks fit in the data and generate explanations. As has been stated elsewhere, “The ability to explain, or build explanations, lies at the heart of qualitative research” (Ritchie & Lewis, 2003, p. 215). This final phase allowed me to explain why the data took the forms that I had identified, and to address recurrent linkages or contradictions I found in the data.

## **Results**

A total of 60 African Americans participated in the focus groups. Thirty-five African American men participated in the study with ages ranging from 27 to 81 and the mean age being 56. Twenty-five African American women participated in the study with ages ranging from 24 to 89 and the mean age being 58. About three quarters of the participants had high blood pressure, about one-half had diabetes, and about one-third had both conditions (Saha, 2007).

The data provided insight into the four concepts which I had identified from prior literature. I found the four concepts in both men's and women's focus groups, at times manifesting differently. For instance, the theme of medical mistrust was much strongly evident in the women's focus groups. In the men's focus groups, however, when participants spoke about mistrust, they also spoke about poor communication and discrimination. I also found relationships among concepts in the participants' reports. For example, when the person spoke about poor communication, perceived discrimination was embedded in that experience. There is, however, no clear sequence in how these barriers manifest. Therefore, I name the connection among the barriers “intersectionalities” in this section; this term represents the multiple forms in which these

barriers manifest within one another. This section is structured with examples of each respective theme and then followed by examples of intersectionalities.

### ***Perceived discrimination***

African Americans in this study reported experiences of discrimination which took place at their doctors' offices but before they entered the doctors' examining rooms. The ambiguous situation of not knowing whether their treatment in the waiting room was in response to their racial/ethnic background caused concern and distress. One participant discussed his experience in a waiting room.

Actually, I've had good experiences with all my doctors. I just recently got a new doctor in the past month, and they saw me for the first time about a month ago. I always feel like I'm getting skipped over. I don't know if it's a Black thing or not, but I always feel like, I was here before somebody else, and they went in before I did, but I sort of try to keep that to myself. But outside of that, people I talk to and the receptionist, or whatever, they're always pretty nice to me. I haven't had any problems outside of feeling like, I don't know, like I said, if it's a Black thing. I'm just being skipped over.

Another man makes it clear that for him such incidents were not isolated from one another. The experience of discrimination happened often when he went to the doctor's office. He underwent a similar process of questioning whether the treatment was discriminatory or not.

That's all the time. That's all the time. Every time I go to a doctor, it seems like I'm always there on time, um, and, you know, here are other people, say, at certain different appointments I go to for different reasons, I'll hear people say, "my appointment's at 4:15," and, you know, my appointment's at 4:00, but somehow, they got in before I did and, I'm thinking, "Are they more injured than I am? Are they sicker than I am? What's going on?" The first thought that comes into my mind is, "Is it because I'm Black?"

As opposed to keeping the tension to himself, he tried to make sense of his experience by asking other people whether the experience was discriminatory or not. He did not want to wrongly interpret his experience, but he wanted to resolve the ambiguity he felt:

I've still been confused. I've still been confused and wondering if it's just me, you know, once again. Like I said, a Black man gets paranoid sometimes for no reason. Well, was I just getting... was I overreacting? Am I over... Am I seeing this completely wrong? That's why I ask people all the time, "What do you think about that statement? How does that make you feel, if you were to hear, 'you know you almost passed.'" You know, it just didn't sound professional to me. It threw me off.

This experience was not exclusive to African American men. When speaking about experiences of discrimination, the men brought up the experience of long waits in the waiting room. The women, however, spoke about experiences interacting with medical staff. They noticed a difference in how the medical staff interacted with European American patients and African American patients.

Well, my primary care doctor, doctor of internal medicine, is very helpful towards me, and she goes out of her way to help me, but I notice when I'm in the receptionists' area, that the receptionists seem more willing to chit-chat with the White clients that come through than they are with me. They'll have them standing there talking to them and laughing and joking, and when I step up and make a comment, you know, it's all business. I feel (laughs), I feel like they're prejudiced...

Unlike the men, African American women also brought up experience of discrimination in the doctor's exam room. The women believed they had to constantly fight to receive fair treatment from the medical staff and doctor. This was a common experience many women reported. An African American woman described her experience receiving care from her doctor.

When I flare all up, I like to have something just because my pain go from my toes all the way up to my neck and shoulders sometime, and I can't hardly function. I need something, and that's why I be saying, give me something, or tell me something I can do. I need help and that's my biggest gripe. I think it's because I'm a Black woman I don't get no medication or no kind of other kind of treatment. So, I'm saying, I think it's that kind of an issue, because you got White druggies, they are all kinds of people are druggies, but they suspect the African American.

Another African American woman agreed with her, as she felt that African American women's pain and symptoms were ignored because they were viewed as drug addicts. She believed women had to overcome many barriers to receive quality care.

When you got us Black sisters that's really sick or really need some help, we always got to go through a whole bunch to get something and I just don't think that's fair. I ain't crying about it, that's life, but, like she said, it seem like to me they got the attitude that you just going there for pills. So, it just seems like to me sometimes that's the attitude that they have.

### ***Race discordance***

Focus group participants varied in their preference or lack of preference for race concordant doctors. Many African Americans said they did not care whether they had a race concordant doctor as long as the doctor was competent. One participant described what she wanted from a doctor, which went beyond race, ethnicity, and culture. She said, "I see a Black doctor now, but I don't think either way that it would make any difference the culture or the race of the doctor. I just want to have a doctor that's a good doctor, that's willing to listen, and has a good understanding." The men's groups echoed this preference as one man said, "If it happened to be a Black doctor, I wouldn't have any problem with it, but I just want to have a good doctor." Those who did prefer race concordant doctors believed that African American doctors are much better communicators and much more caring. Experiences of poor communication and

discrimination seemed to influence their preference (I discuss this intersectionality in more detail below). As one woman expressed, "They are more compassionate. They always want to give you as much information and they seem to have empathy with you and everything." One African American man, in particular, spoke of benefits beyond communication. He believed it was important for African Americans, especially children, to see a race concordant doctor because they can have positive role models in their lives.

Yeah, I went to one when I was a kid. That was the only time, but, he did take care of my grandmother and he had to come to the house to take care of her. He was there any time she needed him. I wouldn't hesitate to go to one. They just don't have that many in this part of the country. So, okay, wait a minute, let's go beyond that. If there isn't that many Black doctors here, then the kids who's growing up, they're not really going to think about being a doctor because there's no role model.

### ***Medical mistrust***

Lack of trust seemed to pervade reports from the African American women's group discussions. African American men also provided accounts of medical mistrust, but in those accounts, mistrust was closely linked to other barriers (I shall discuss these intersectionalities in detail below). One African American woman described why she withholds information from doctors; her account shows evidence that mistrust was learned from members of her family. She said, "Well, I had doctor that I didn't... I saw her for many, many years, but it made me realize that that's one thing, you don't tell everything. I should have known that because my father taught me 'Don't let your right hand know what your left hand is doing when you go to the doctor.'" Another woman agreed saying, "Well, I didn't trust him no further than I could see him because, especially when he started, uh, telling me, telling me some medication, you know, where I can go get some cheap medication." Another woman recommended bringing someone

else along to the doctor visit to advocate for the patient and bring some form of support because she does not trust doctors in treating patients with quality care. She said, "I want to add that many people go to the doctor and, if at all possible, they should never go to the doctor alone."

### ***Poor Communication***

Poor communication is a crucial barrier that affects patients' relationships with doctors. Often when focus group members spoke about their account of poor communication, they spoke about instances where the doctors did not provide the time to allow the patient to speak. An African American man described an instance where he had to prepare himself to interrupt the doctor so he can have a moment to talk.

Well, it really kind of pisses you off, because a lot of times I've gone to the doctor with something specifically that I had to say to them, and hell, when I go in there to say, well, they get off on something else and I didn't even get to ask what I really went in there for. So it kind of pisses me off. And so, I go back for the same thing the next time. One time, I just wrote it down, I said, "Wait a minute, hold it! Let me tell you for a minute!" Because otherwise, they just take over and tell you what it is.

Another African American man spoke about how his symptoms were ignored during a routine appointment. Although the doctors focused on his diabetes, they completely ignored his other complaints.

Okay, I got a situation real quick that I'm dealing with right now. I've had a torn rotator cuff in my shoulder for three years. I know exactly when I tore it, and I been telling doctors, three different doctors in the past three years. Like I said, I got this new one, and I have to start all over with this new doctor and explain, after we figure out my whole diabetic and my other problem that I'm having with. Now, I have to start all over and say, "Now, I have this torn rotator cuff. Can you help me?" I've been telling three different doctors for the past, three years that I've this problem, and all they talk about is diabetes. And I'm not there to talk about my diabetes, I might be there to add that in somewhere, but that's not the reason why I'm there. They seem to stick on the whole subject because "You're a

diabetic. How is your blood sugar? Let's go do the blood tests. Let's have your blood drawn. Are you doing this good?" Yes! That's all fine, okay, and if it's not fine, tell me how to fix that later, but I'm here today because my rotator cuff. My cuff is torn, and it hurts real bad. Now, it's affecting my life a whole lot more. I can't sleep as well as I would like to, and I can't get comfortable like I like to, but I'm being completely ignored, and it's not just one doctor, and it's not a man or a female, it's just, they only see your diabetes, and that's a problem to me. I mean, if they're my primary, I have other problems that I want to get taken care of, and this is one of them.

An African American man described how a doctor's use of jargon constrained the communication. He, like some of the other focus group members, felt uncomfortable when the doctor spoke in formal terms.

Well, I don't know, sometimes a doctor can make you feel comfortable, and sometimes they make you feel uncomfortable, and it's all in the way they talk to you. I don't have a lot of education, and when he [doctor] gets to using them big words, that's a bring-down. If I understand you, then I can cope with you, but if I don't understand you, I can't.

An African American woman described an incident in which the doctor did not listen to her, which resulted in an altercation that required her to eventually seek another medical provider.

And it was a male doctor at the time, and I didn't feel that he was really listening to me trying to help me solve my blood pressure problems. It seemed that I remember that my blood pressure was really high at the time, and it seemed that he just started accusing me of, "Well your blood pressure shouldn't be this high. You must be on drugs. Your pressure shouldn't be this high. You're so young and everything." So we end up having an argument, because I wasn't on drugs. I was there to try to find out why my blood pressure was so high and bothering me. And so he just started making accusations and I feel like he got me more upset. That's when I switched over to a different hospital and insurance at that time.

## **Intersectionalities**

### ***Poor communication and perceived discrimination***

Poor communication and perceived discrimination seemed to overlap with one another. Often the focus group members seemed to attribute the poor communication to how the doctors respond to their racial/ethnic background. They believed that doctors (often race discordant doctors) seemed to devalue their symptoms or ignore their comments because they were African Americans. This man describes a negative experience when interacting with the doctor.

I don't know, I guess I was a little upset because I go in, I went in with a problem, and it seems like my problem was downplayed and I was told something else was wrong, when I knew better. It was more or less just being ushered out as quick as possible. It's as though when they see an African American come in there, it's like we're trying to get over and that's the impression I get every time I go. It's a little upsetting.

An African woman described a situation in which her symptoms were devalued. She believed that as an African American she was not treated with quality care. Her experience showed the lack of competency from the medical provider in treating African American patients, an incompetency which seemed to be compounded by poor communication. The medical provider failed to recognize the woman's symptoms and did not provide her with any more information.

They act like they're afraid to touch you or they can't tell you. You say, "I got a bump right here where I can't see." They can't see anything on you and I have heard a lot of Black people have issues about that, where they act like they can't see anything on you. You just kind of a nobody. You don't have nothing on you. "What's that?" You tell them, "I've got a bump right here." They say, "Hmm... bump? I can't see nothing," And a lot of time, they go in, they won't touch you.

### ***Medical mistrust and poor communication***

The lack of an explanation for procedures and recommendations can reinforce the level of mistrust that a patient may have brought with himself or herself into the patient-

provider relationship. One woman said that even with good doctors, she was reluctant to trust their recommendations. She provides evidence that the history of discrimination played a role in her mistrust:

I have a problem with that. That doctor might have been a really good doctor, but when somebody come and talk about "More Blacks have this," I got a problem with that. I don't believe everything they say because it ain't always true. I know this is not the question that you just asked (laughter), but I got to tell you. I went to the doctor and this person I guess she didn't have nothing to do. And she asked me, "Did I want to take an AIDS test?" And I said, "Why should I take an AIDS test?" She said, "Because she didn't have nothing to do." I said, "Well you ain't giving me no AIDS test!" I said, "Why do they tell me they paying for it? I don't have no reason to take no AIDS test. I mean, just out of the blue. She didn't have nothing to do! (laughter) While I'm on that subject, I have this experience that Gloria had. When I get ready to have the shots I tell them you got one chance. Do not miss that vein! And if you can't get it the first time you going to get somebody else... one chance. You ain't sticking me six times.

### ***Poor communication and race discordance***

Those who preferred a race concordant doctor spoke about the ease in communicating with a doctor of the same racial/ethnic background. Patients were able to be a part of the decision-making process. The ease in communicating with a race concordant doctor came from the comfort in knowing that the doctor knew the patient's culture and spoke in a way that was understandable. An African American man described how race concordant doctors interacted in a way that was preferable for African American patients. He explained how European American doctors might misinterpret his words as opposed to African American doctors who are able to understand his words and respond clearly.

Like he can be in my format. He can talk to me like I talk to him, everything is cool. Because, even though I might, say the same words, they may not come out the same way, okay? And if I talk to a White

doctor, he going to look at me and he is going to say, "Well, Okay. Well, hmm... yeah right, this and that." But if I talk in a certain kind of way to a Black doctor, he's going to come to you because he knows this is where he's from. He knows what it takes to get there, okay?

Another man explained why race concordant doctors were preferred when it came to communication. He believed that a race concordant doctor would have the same cultural prism that the patient has, enabling him to have a better communication with the patient. The man saw the relationship going beyond just a patient-provider relationship. He saw it more as a friendship, in which he was comfortable to ask for clarification.

I think one of the benefits of having a doctor of your own ethnicity is just a level of communication because some doctors may not understand what's going on from a cultural perspective. They just don't know. I mean, it's just like, if you had an Asian doctor, sometimes there's a language barrier. I've had seen Asian doctors before and it was hard to understand what people were saying. Sometimes they understand, like I had a doctor that was real short with me in terms of his patience because he just couldn't understand why I was in the situation I was in. But see, if he had understood our culture, then he would have been a lot more understanding and a lot more patient in terms of dealing with my situation. So I think culture it has a lot to do with understanding. I'm not saying it's the biggest thing, but if you can get a doctor of color... I had a real good doctor of color. In fact, his son was on my basketball team, Dr. Johnson. He retired several years ago, but it was just good to be able to go in there and see somebody that looked like you, you know. That they care about you, and then to be able to have a conversation about what's going on, and they can break it down sometimes.

An African American woman described her experience with an African American doctor. The doctor was able to make her feel comfortable. The feeling of comfort made her feel as though the doctor cared about her health. The feeling of comfort allowed her to be open to doctor and receive the care that she needed.

She made me feel more comfortable. I felt like I could talk more freely to her without being judged. I'm a recovering addict, so I was able to tell her that and get the help that I needed. Even when I was in treatment, she

would make sure that she didn't prescribe me anything that was narcotics. I felt she cared, really cared.

### ***Race discordance, perceived discrimination, and medical mistrust***

While some African Americans preferred to see an African American doctor, others preferred a European American doctor. This African American man explained how his expectations for an African American doctor were too high and would be disappointed if the doctor did not meet his expectations. He had lower expectations for European American doctors, expecting them to treat him poorly. This anecdote shows the complexity that exist and how discrimination is embedded in the discussion of race discordance.

I think my expectations would be too high if I saw a Black doctor. But then, I'd expect him to understand everything I'm saying and to understand how I feel. And if he doesn't for one second, it's just going to piss me off. And then I'm going to think, "He's got a serious problem." So, me, personally, I just want to go to the best doctor, but, no, I'd rather not see a Black doctor because if he does one single thing that I don't appreciate, I'm going to have a fit, you know. I'm going to be real angry about this Black doctor, and I'm going to go tell everybody, "I saw this Black doctor and I can't believe this man did this, and I can't believe this man didn't listen to me, and all he did was piss me off, and I'm done with him." I'll be done with the doctor. I'd be more angry if he hurt my feelings than if somebody I'm already used to hurt my feelings. I could deal with that better because I'm used to being offended by White doctors. It's nothing new to me. I've been offended by White people all my life. I don't appreciate being offended by somebody of my own race.

Another man agreed with this statement. He described just how he also accepted the treatment he received from European Americans, but his expectations were too high for an African American doctor. For him, it went beyond the doctor's competence; he held important how an African American doctor would communicate with him. If an African

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American doctor communicated in a way that was not in accordance with how African Americans should communicate with one another, he would be disappointed. In order to avoid such situation, he would rather see a race discordant doctor.

I've been offended by White people all my life. I don't appreciate being offended by somebody of my own race. I want to be able to talk to them, and I want to be able to say things that I probably wouldn't say to a White man, you know. And if he comes off wrong or treats me like, "How're you doing there, Mr. Smith?" (use an affected voice), or something like that, that's going to throw me off, and I'm going to go, "What the heck is wrong with this man? Did he lose his way at some point?" or "What happened to him?" So, I'd just feel safer going to what I'm used to going to, because I don't want to get my feelings hurt by a brother or a sister. I don't want to get my feelings hurt.

Another African American man had negative experiences with race concordant doctors. Although he did not describe actual experiences with the doctors, he saw them as pretentious. His statement gives insight as to why the patient would view a race concordant doctor in that manner.

Okay, something else that gets me. It would be nice to have more Black doctors, but the ones that I've had that I've visited, they have this mentality, you know, they looking down their noses at you. It's like, "I'm a doctor, and you are a piece of." I mean, this dude, he's a closet bigot against his own people, as far as I'm concerned. I think it's part of the program. I don't look for them to be better than anyone. Just do your job like you're supposed to do, that's all I ask. I think you expect a Black doctor to make you more comfortable because he's Black. Period!

### **Discussion**

What do these findings tell us about patient-provider relationships for African Americans? By using the four concepts of perceived discrimination, race discordance, medical mistrust, and poor communication, we are able to understand how African American patients experience these barriers in primary care. This study allowed me to

gain valuable insight into the four concepts; particularly in understanding exactly what African American patients consider discriminatory, why they prefer race concordant physicians, what influences their lack of trust towards doctors, and what factors negatively affect communication with doctors. Further, this study was able to show the complexities that exist within each concept. Each concept overlapped the next in participants' commentary. This intersectionality suggests that future studies would do well to study these concepts together, in order to develop a fuller understanding on African Americans' experiences in primary care. Before I discuss their intersectionality further, it is important to reflect on each of the four concepts, respectively.

In regards to the concept of *perceived discrimination*, what exactly do African American patients consider discriminatory? African Americans in this study did perceive discrimination when receiving health care, and many African Americans felt they would not receive the best care if they were sick (cf. Blendon et al., 2007). This study also showed that the experience of discrimination actually begins before the patient enters the examining room. For many African Americans, having to wait a long time in the waiting room made them question whether they were being discriminated against or not. African American women, in particular, noticed how the medical staff interacted with European American patients. They found the interaction to be friendly and warm, as opposed to their own interaction of being cold and business-like. Some would even ask members of their own ethnic group for help in validating their experience. Although the experience may or may not have been discriminatory, by having a person validate their experience helped them resolve the internal tension they felt.

Study participants reported that they experience discrimination in the examining room as well. There were instances, particularly for African American women, in which participants felt they were treated like drug addicts. They believe they are less likely to receive medication or treatment because of how doctors and medical staff responded to their racial/ethnic background. These experiences caused distress and concern. Dion (2002) would suggest that these stressful situations would affect the person's behavior. These experiences can in turn lead to a lack of trust towards the doctor and perhaps reduce the chances of adhering to the doctor's recommendations. These findings provide insight as to why perceived discrimination contributes to differences in patient behavior. These findings, for example, corroborates studies that find perceived discrimination being associated with lower medication adherence, provide lower patient ratings of visit informativeness, and underuse healthcare services for African Americans (Casagrande et al., 2007; Burgess et al., 2008). Insofar as discrimination itself is the result not of who one is (subject variables) but how powerful others respond to who one is (stimulus variables), discrimination removes control from the patient and reduces patient autonomy. This too is consistent with findings from past studies (Penner et al., 2009; Hausmann et al., 2011).

*Race discordance* was not a problem for some focus group members. As long as the doctor was competent, it did not matter what ethnic group the doctor belonged to. Those participants who did prefer a race concordant doctor provided insight as to why African Americans patients with race concordant doctors have higher levels of trust, satisfaction, and intent to adhere than those with race discordant doctors (Street et al., 2008). For those who did prefer race concordant doctors, they felt that race concordant

doctors were able to communicate better and understand the patients' experience much better, which enables the doctor to be empathic and compassionate. These patients would view African American doctors as being more concerned about their well-being. Similar to perceived discrimination, poor outcomes of race discordant relationships may be a result of how doctors respond to who the patient is (stimulus variables) or vice versa, reducing the opportunity for openness, trust and good communication that enable doctor-patient partnership. Social Identity Theory would suggest a person would display favoritism toward members of their in-group (Tajfel, 1982). How would Social Identity Theory explain why other focus group members did not prefer a race concordant doctor? Perhaps, those who have a stronger attachment to their in-group would favor other members of their in-group, while those who do not identify with a certain group may display little to no favoritism toward members of that group. Future studies might explore whether African Americans with high levels of racial identity would prefer a race concordant doctor more so than those with lower levels of racial identity. Alternately, it may be that some participants viewed African American doctors as problematically distant from themselves in level of education, and thus, too difficult with whom to establish rapport. In either case, reports from participants who did favor race concordant doctors provide us a better understanding as to why (Saha et al., 1999; Cooper-Patrick et al., 1999).

Pertaining to the concept of *poor communication*, prior studies have shown that African American patients report unfavorable interactions with their doctors (Gordon et al., 2006; van Ryn and Burke, 2000). What are some of the factors that may negatively affect communication between patient and doctor? When focus group members spoke

about negative experiences about communicating with doctors, they often spoke about how doctors did not listen to them. The focus group members mentioned how the doctors seemed to be pressed for time and often did not let them speak. The experience of not being heard decreases person's willingness to participate in his or her own treatment. Similarly, a doctor's use of jargon can prevent the patient from understanding and engaging in the conversation of his or her own health (Travaline, Ruchinskas & D'Alonzo; 2005). This provides better understanding as to why African American patients report that doctors do not spend enough time with them, do not respect their intelligence, and do not provide sufficient explanations (Gordon et al., 2006; van Ryn and Burke, 2000). Because they do not have a chance to be heard or the opportunity to ask for clarification, they are less likely to be engaged in the treatment. This in turn may lead them to receive less information from their doctors and be less active participants (Gordon et al., 2009). As patients decrease their communication behaviors (i.e. asking questions, expressing concerns, assertions), this may affect future doctor-patient interactions.

What factors influence a person to *mistrust* medical providers? African Americans who are high in medical mistrust tend to have more negative views and expectations of their health providers (Thompson, Bazile, & Akbar, 2004). However, studies have yet to identify the discursive practices that occur in the healthcare system that influence this mistrust. In this study, medical mistrust seemed to be connected with the other concepts. However, there were some isolated examples of medical mistrust, primarily in the women's focus groups. Mistrust seemed to not be based on personal past experience towards medical providers, but learned from family and friends. For instance, an African

American woman was reluctant to provide the doctor with complete information about her health because she learned from her father to never be completely open with doctors. Although she did not elaborate on this statement, it is clear she withheld information it may have benefited her to disclose. Another woman was reluctant to accept a doctor's recommendation. She felt as though doctors are always trying to push pills toward African Americans and not trying alternative methods to improving their health. The doctor's lack of explaining the regimen or the lack of considering alternative methods in treatment can lead to the patient mistrusting doctors. Mistrust can in turn lead to dissatisfaction with doctor's care and noncompliance (Hall et al., 2001; Hammond, 2010).

It is difficult to talk about these concepts individually because they were embedded within one another in participants' reports. Many participants who talked about medical mistrust also talked about discrimination; many who talked about their experiences with race discordant doctors also talked about poor communication. Prior literature has shown how each barrier negatively affects patient-provider relationship, but until now, no studies have looked at these four concepts together.

The interrelated nature of these ideas evokes the social psychological concept of self-fulfilling prophecy (Merton, 1968; Rosenthal, 1974). Possibly, because doctors do not explain or clarify their recommendations, communication suffers and patients are less adherent or satisfied. The unfavorable experience reifies a sense of medical mistrust that patients may have initially brought to the interaction. In turn, patients are less likely to be engaged participants in the next interaction. This would contribute again to a lower adherence of medication, lower satisfaction with quality of care satisfaction, and lower

use of healthcare services (Whetten et al., 2008; LaVeist, Nickerson, & Bowie, 2000; Yang, Matthews, & Hillemeier, 2011). Future studies might explore the self-fulfilling dynamic, and identify junctures amenable to intervention.

Race discordance and poor communication were frequently mentioned together in the focus group discussions. This finding supports LaVeist and Nuru-Jeter's (2002) theory that the source of trust among patients may be an intrinsic sense of connection to members of their own racial/ethnic group, with the expectation that a race concordant doctor will exercise a greater sense of agency with regard to patient care. Patients who prefer race concordant doctors may feel they are able to be a part of the decision-making process. They believe that communicating is comfortable and easier because they believe the race concordant doctor knows their culture.

Future studies could look at how both poor communication and medical mistrust play a role toward patients' health and health behavior. For example, studies could use mistrust as a moderator to determine whether the relationship between poor communication and negative health behaviors depend on the person's level of mistrust. Interventions that are designed for African Americans to address patient provider communication may help to overcome medical mistrust. The intervention can be developed with strong community input that includes ways in which patient and doctor can build a partnership and promote informed decision-making and adherence. Input from the community can also help modify medical training for future doctors and medical staff to help with their interaction with African American patients, which in turn can also help build trust.

The last intersectionality is race discordance, medical mistrust, and perceived discrimination. Their overlap clearly depicts the necessary complexity in discussion of these barriers. While some African Americans preferred to see African American doctors, others preferred European American doctors. They preferred European American doctors not because they provide better quality of care, but because their lowered expectations of European Americans meant less risk of disappointment. One study participant explained he was used to being treated poorly by European American doctors (discrimination), but he could not accept the possibility of being treated poorly by a member of his own racial/ethnic group. Social Identity Theory would suggest that he is trying to maintain a positive image of his in-group by avoiding any situation that would violate this image. Social Identity Theory also rings true in another example. Another focus group member said he would not like it if an African American doctor used medical jargon in the exam room. The use of jargon would create social distance between doctor and patient, meaning the doctor would be a kind of traitor to his own ethnic group. It seems as though medical jargon is associated with the out-group and by using jargon the African American doctor would remove himself from in-group membership. This complexity might provide insight into prior research that finds little evidence to support differences in health outcomes between race concordant and race discordant patient-provider relationships (Meghani et al., 2009).

Further understanding of the intersectionality of these barriers can help us identify ways in which they influence patient-provider relationships. Future studies could explore ways to design interventions to help improve discordant patient-provider relationships. For example, interventions can modify a doctor's approach to interacting with a patient

(e.g., less use of jargon, explaining all treatment regimens, and giving the patient time to offer their own perspective on their own health and treatment), which in turn can improve patient trust. Because race discordance and medical mistrust, as shown, are linked to perceived discrimination, it is also important to develop interventions to help African American patients cope with daily stressors like discrimination (Mays, 1995). Although the coping of discrimination may not improve discordant patient-provider relationships or reduce mistrust, it can at least improve adherence to medication or the continuation of the use of healthcare. Ideally of course the problem of discrimination would be prevented rather than addressed after the fact.

### **Limitations**

Important limitations need to be taken into consideration when talking about this study. Most of the participants lived in Portland, Oregon, a city with relatively low racial diversity (American FactFinder, 2008). Because of the low racial diversity (i.e., small African American population), African Americans' experience may differ from African Americans of other geographical regions. This means the focus group participants were far more likely to have received service from European American healthcare providers than from African American healthcare providers. This in turn lowered the chance of reading discussion narratives about past experience with race concordant doctors. This lack of information has prevented us from fully understanding African American patients' experiences with race concordant doctors.

Because this study relied on word of mouth recruitment, this reduced the chances of diversity of age, socioeconomic status, or other relevant variables (Sadler et al., 2010) within any given focus group or across groups. While this is a study limitation it is also a

study strength. Focus group discussions are often enhanced by the participation of "homogenous strangers" (Morgan, 1997) who are similar enough to be at ease disclosing their views and experiences to one another.

As a method of collecting data, focus groups depend upon group interaction. Depending upon the population, the topic, and potentially also upon situational factors, normative influences on participants' commentary can be high in focus groups. Real or imagined social pressures can influence individuals' decisions to report perspectives discrepant from a perceived norm or indeed, discrepant from what participants believe researchers wish to hear. This is a common criticism of focus groups (Ritchie & Lewis, 2003). In part to minimize this problem, the research team trained the focus group moderators to welcome all points of view on topics of discussion and to solicit a wide range of experiences from study participants. Even so, we did have the problem that moderators were relatively inexperienced at soliciting dissenting viewpoints. In addition, because moderators were new, the earliest focus groups were held in a setting with the study's Principal Investigator close by; the Principal Investigator is not an African American. His presence is likely to have affected some of the group discussions, although it is impossible to know to what extent this was the case.

There is also the concern to know how far the findings from a study can be generalized to the specific population from which the study sample was drawn. Richie and Lewis (2003) state that generalization in qualitative research involves three key issues: whether what is found in a research sample can be generalized to, or held to be equally true of, the parent population from which the sample is drawn; whether the findings from a particular study can be generalized, or inferred, to other settings or

contexts beyond the sampled one; and whether theoretical generalization (i.e., theoretical propositions, principles or statements from the findings of a study) can be used to develop further theory. The basis for generalization in qualitative research is very different, however, from that in quantitative research (Lincoln & Guba, 1985). Ritchie and Lewis (2003) would add:

Qualitative research cannot be generalized on a statistical basis - it is not the prevalence of particular views or experiences, nor the extent of their location within particular parts of the sample, about which wider inference can be drawn. Rather, it is the content or 'map' of the range of views, experiences, outcomes or other phenomena under study and the factors and circumstances that shape and influence them, that can be inferred to the researched population (p. 269).

To reach a level of generalizability (known as "transferability" in qualitative research), accuracy is needed (Winter, 2000). Accuracy depends on the quality of fieldwork, analysis and interpretation. To increase validity, researchers can use triangulation through multiple analysis, which is using different observers, interviewers, analysts to compare and check data collection and interpretation (Golafshani, 2003) or respondent validation, which involves taking research evidence back to the research participants to see if the interpretation assigned is confirmed by those who contributed to it in the first place (Ritchie & Lewis, 2003). This process increases credibility and validity, thus, increasing the trustworthiness of the entire study (Lincoln & Guba, 1985). In this secondary analysis I was unable to check the accuracy of transcripts or to hear the participants' own voices due to the unavailability of group discussion audiotapes. However, another member of the research team has confirmed my interpretation of study findings, and I have requested the Principal Investigator of the original project, who knows the data very well, to review my findings also.

A related issue is the degree to which the focus group sample is representative of the parent population. The representation should not be based on statistical significance level but on inclusivity, namely, whether the sample provides "symbolic representation" by containing the diversity of perspectives that are central to explanation (Ritchie & Lewis, 2003). Inclusivity is practiced by reporting and explaining the atypical as much as it does reporting the more recurrent themes. In this study, we approximated inclusivity through reporting both areas of agreement and areas of disagreement. All things considered, qualitative research is able to capture the perspective of participants themselves in their own words, something that quantitative research cannot offer.

Despite the limitations, the study has important implications for healthcare practice. Healthcare providers and healthcare staff must understand and acknowledge the past experience and perspective of African American patients. This understanding can help increase the chances of African American patients using healthcare service again. One step towards getting a fuller understanding is further examining the four barriers that is prevalent in the African American population. For now, these barriers have been shown to affect the use of services, which may play a role in the healthcare disparity that exists in the United States for African Americans. A better understanding of the four barriers from African American patient perspectives may help ameliorate the problem by suggesting ways in which quality of care may be improved.

#### *Secondary data analysis*

This study was a secondary data analysis stemming from an original study that asked adult community members of three ethnic groups (African American, Latino/Latina, and European American), each of whom had diabetes or hypertension or

both, about their experiences with and perspectives on healthcare providers, specifically doctors. Focus group questions ranged from topics regarding race concordance to trust and respect and were structured to allow moderators the freedom to probe interesting areas. As a relatively recent arrival on the research team, I coded and analyzed the original data from all three ethnic groups. Because my study has involved secondary analysis it is important to mention some of the limitations in using secondary data analysis in psychological research.

One major limitation is that the researchers designed the interview guide and collected data prior to my own arrival on the research team. Particular information that I might have liked to have had was not collected; for example, in some instances the moderator could have probed the respondents for more information about trust and other aspects that negatively affects patient-provider communication. A second limitation in using secondary data is that because I did not participate in the planning and execution of the data collection process, I did not know exactly how it was done. This required me to find the information through other means, such as attending research meetings, asking team members, and reading meeting notes or meeting minutes. All things considered, disadvantages to using secondary data include the inability to select specific questions and lacking control over the precise timing or design of the data collection (Boslaugh, 2007; Tomlinson-Keasey, 1996).

There were also several benefits to working with secondary data. One was economy: with data already available I did not need to devote resources to the data collection phase of research. The time it has taken to learn about the community of interest and analyze the data is minimal compared with the time it would have taken to

gain initial access to an “elusive population” (Fielding, 2004), recruit participants, conduct the group discussions and transcribe them. For this specific study, working with secondary data facilitated my training by allowing me to focus more time on data analysis and indirectly learn the proper way of conducting a study. Furthermore, as Wortman and Bryant (1978) state, a system of quality control can be established when conducting secondary data analysis, allowing the secondary researcher to inspect the work of the primary researcher and verify the validity of his or her own procedures as well. Because I was not one of the primary researchers in the original data collection, I was able to inspect the original work in this manner. Lastly, this secondary analysis also adds to existing knowledge by examining issues that were not addressed by the original researchers (Cook, 1976; Johnson, 1964). It is profitable to conduct a reassessment of old data in the light of new findings and conceptual extensions of prior literature.

It is important to mention that although I did not have to invest time creating a research instrument or collecting the data, I did invest significant effort in coding the primary data. This allowed me to acquaint myself with the questions that were asked to participants and the responses given by them. Furthermore, this allowed me to feel confident that the research question for the secondary data analysis fits well with the existing data. I learned about the planning and execution of the data collection during regular EQUALED meetings and reading through archival documents pertaining to the original study’s research method and procedure. Having a strong literature base in the area of African American health issues also enabled me to ground my qualitative analytic decisions in conceptual understanding, thus strengthening my capabilities in analyzing these data.

### **Implications**

Despite its limitations, this study provides important implications for African American-specific interventions and future studies. Participants provided insight into how the four barriers manifest. Health service providers must understand and acknowledge the experience of minority patients who underuse their service. They should use these insights to implement change in the healthcare system. As shown, the change does not only apply to doctors, but to medical staff as well. This understanding can help create culturally appropriate medical training for current and future medical staff, as well as with current and future doctors, to help with their interaction with African American patients. Such training might focus on ways to enhance effective communication and strengthen patient opportunities for patient-provider concordance, while also building medical trust and reducing real and perceived discrimination. Future studies might also quantitatively examine these barriers together to see how they relate to the underuse of health care services. Further, future studies might identify staff and/or providers who are considered by African American patients to do an exceptional job in the areas of building trust and communication; these staff and/or providers might then be observed or interviewed so that their best practices can be identified. These best practices, in turn, might be offered in future trainings of doctors and their clinic staff.

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## Appendix

The focus group guide is used with permission by Somnath Saha.

The focus group guide was intended to probe people's actual experiences with health care, particularly interacting with physicians, as well as their values and preferences regarding doctor-patient interactions. The focus group guide included the following:

- Introduction
- Experience with most recent visit to the doctor
- Good experiences with doctors
  - Actual experiences
  - What makes a good experience
- Bad experiences with doctors
  - Actual experiences
  - What would have made for a better experience
- Physician race/ethnicity
  - Experiences
  - Preferences
- Personal/sensitive topics discussed with doctors
  - Drug and alcohol use
  - Sexual history, activity, and function
  - Delivering bad news
  - Complementary and alternative therapies
  - End-of-life preferences and living wills
- Trust

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- Experiences of distrust
- What engenders trust
- Respect
  - Experiences of disrespect
  - How is respect demonstrated
- Following doctors' recommendations – medications and procedures, lifestyle changes
  - Experience not following doctors' recommendations
  - What prompted non-adherence to recommendations
- One piece of advice you'd like to give your doctor