Published in final edited form as:
Soc Sci Med. 2010 July ; 71(1): 1–9. doi:10.1016/j.socscimed.2010.03.014.

Details for Manuscript Number: SSM-D-08-01910 R2 "Race and Shared Decision-Making: Perspectives of African-Americans with Diabetes"

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Abstract

Shared decision-making (SDM) is an important component of patient-centered healthcare and is positively associated with improved health outcomes (e.g. diabetes and hypertension control). In shared decision-making, patients and physicians engage in bidirectional dialogue about patients' symptoms and treatment options, and select treatment plans that address patient preferences. Existing research shows that African-Americans experience SDM less often than whites, a fact which may contribute to racial disparities in diabetes outcomes. Yet little is known about the reasons for racial disparities in shared decision-making. We explored patient perceptions of how race may influence SDM between African-American patients and their physicians. We conducted in-depth interviews (n=24) and five focus groups (n= 27) among a purposeful sample of African-American diabetes patients aged over 21 years, at an urban academic medical center in Chicago. Each interview/focus group was audio-taped, transcribed verbatim and imported into Atlas.ti software. Coding was conducted iteratively; each transcription was independently coded by two research team members. Although there was heterogeneity in patients' perceptions about the influence of race on SDM, in each of the SDM domains (information-sharing, deliberation/physician recommendations, and decision-making), participants identified a range of race-related issues that may influence SDM. Participants identified physician bias/discrimination and/or cultural discordance as issues that may influence physician-related SDM behaviors (e.g. less likely to share information such as test results and more likely to be domineering with African-American patients). They identified mistrust of white physicians, negative attitudes and internalized racism as patient-related issues that may influence

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African-American patients' SDM behaviors (e.g. less forthcoming with physicians about health information, more deference to physicians, less likely to adhere to treatment regimens). This study suggests that race-related patient and physician-related barriers may serve as significant barriers to shared decision-making between African-American patients and their physicians. Finding innovative ways to address such communication barriers is an important area of future research.

Keywords

USA; shared decision-making; patient/provider communication; diabetes; race; African-Americans; health disparities; physicians

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Introduction

Diabetes is a major cause of morbidity and mortality in the United States. It is the seventh leading cause of death (Aubert, Herman, Waters, Moore, Sutton, Peterson et al., 1998), and the cost of medical care is $100 billion annually (Caravalho & Saylor, 2000). Approximately 15 million adults are living with diabetes, and the prevalence rates have continued to escalate over the past decade, with racial/ethnic minority populations suffering a disproportionate burden of disease (McBean, Li, Gilbertson, & Collins, 2004). African-Americans are twice as likely to be diagnosed with diabetes than whites, and are more likely to have poorly controlled diabetes and diabetic complications such as blindness, end-stage renal disease and limb amputation (Bonds, Zaccaro, Karter, Selby, Saad, & Goff, 2003; Gary, McGuire, McCauley, & Brancati, 2004; Harris, 2001). African-Americans are also more likely to have uncontrolled co-morbid conditions such as hypertension and hyperlipidemia, which increases the complexity of disease management (Brancati, Kao, Folsom, Watson, & Szklo, 2000; Heisler, Smith, Hayward, Krein, & Kerr, 2003; Jha, Varosy, Kanaya, Hunninghake, Hlatky, Waters et al., 2003; Nelson, Norris, & Mangione, 2002).

Positive patient-provider relationships can facilitate diabetes management and potentially reduce diabetes disparities (Greenfield, Kaplan, Ware, Yano, & Frank, 1988; Stewart, 1995). Persons with diabetes who participate in shared decision-making (where patients actively participate in healthcare discussions and decisions with their physicians) have greater diabetes self-efficacy, participate more in diabetes self-management, and are more likely to adhere to plans of care (Benbassat, Pilpel, & Tidhar, 1998). Shared decision-making (SDM) has been positively associated with improved diabetes control, enhanced preventive care utilization, lowered blood pressure, fewer hospitalizations, and increased patient satisfaction (Adams, Smith, & Ruffin, 2001; Greenfield, Kaplan, & Ware, 1985; Greenfield, Kaplan, Ware et al., 1988; Lerman, Brody, Caputo, Smith, Lazaro, & Wolfson, 1990; Stewart, Brown, Donner, McWhinney, Oates, Weston et al., 2000). In its report *Crossing the Quality Chasm*, the Institute of Medicine stressed the importance of patients having “the education and support they require to make decisions and participate in their own care” (Richardson, Berwick, Bisgard, Bristow, Buck, Cassel et al., 2001). Since then, SDM has been increasingly advocated by healthcare providers and organizations (Davidson, Powers, Hedayat, Tieszen, Kon, Shepard et al., 2007; Larson, Fihn, Kirk, Levinson, Loge, Reynolds et al., 2004; Michel & Moss, 2005; Richardson, Berwick, Bisgard et al., 2001; Sheridan, Harris, & Woolf, 2004; van der Weijden, van Veenendaal, & Timmermans, 2007).

Unfortunately, results from previous studies show that racial/ethnic minority patients are more likely to experience barriers to communication in patient/physician communication (e.g. shared decision making) as compared to white patients. For example, African-Americans are more likely to rate their physicians as less participatory than whites, even when controlling for socioeconomic status and duration of the patient-provider relationship (Cooper-Patrick, Gallo, Gonzales, Vu, Powe, Nelson et al., 1999). Analyses of audio-taped clinic visits document that African-Americans experience shorter outpatient visits and less positive clinical encounters with white physicians including less respect, responsiveness and listening than their white patient peers (Cooper, Roter, Johnson, Ford, Steinwachs, & Powe, 2003; Johnson, Roter, Powe, & Cooper, 2004; Levinson, Hudak, Feldman, Frankel, Kuby, Bereknyei et al., 2008; Oliver, Goodwin, Gotler, Gregory, & Stange, 2001). Yet, studies examining *patients' perceptions* of how race affects shared decision-making are limited. Research in fields outside of medicine suggests that race plays a significant role in communication patterns and interpersonal interactions between African-Americans and whites, particularly in situations of perceived power differences, such as interactions with law enforcement (e.g. police officers, judges, lawyers), commercial retail (e.g. store clerks and restaurant staff) and financial agents (e.g. bank tellers, loan officers) (Gamble, 1997; Purdie-Vaughns, Steele, Davies, Ditlmann, & Crosby, 2008). Thus, it is likely that a similar paradigm exists for African-Americans' perceptions about communication patterns with physicians. Jacobs et al. explored physician trust among African-Americans, and noted that trusting relationships were important to some aspects of patient communication, including openness and honesty with one's physician, and decisions to follow treatment recommendations (Jacobs, Rolle, Ferrans, Whitaker, & Warnecke, 2006).

There is also an extensive literature about African-Americans' perceptions about their treatment within healthcare settings, including issues of disrespect and discrimination (Blandhard & Lurie, 2004). African-Americans are more likely to report experiencing racial discrimination within healthcare than other racial/ethnic groups, with reports ranging from 13-69% in comparison to 1-2% of whites (Ren, Amick, & Williams, 1999; Bird & Bogart, 2001). Perceived discrimination in healthcare is positively correlated with poor health including depression, self-rated health, days spent unwell in bed, and hypertension (Krieger & Stephen, 1996; Ren, Amick, & Williams, 1999; Bird, Bogart, & Delahanty, 2004). Self-reports of discrimination have been associated with delays in prescription medication utilization and medical testing/treatment, indicating that such experiences represent an additional barrier to accessing healthcare (Bird, Bogart, & Delahanty, 2004; Van Houtven, Voils, Oddone, Weinfurt, Friedman, Schulman et al., 2005).

This study utilized qualitative methodologies to examine the perceptions of African-American patients with diabetes about the influence of race on patient/physician communication and shared decision-making. This investigation was guided by SDM models that contain 3 domains (Charles, Gafni, & Whelan, 1997; Peek, Quinn, Gorawara-Bhat, Odoms-Young, Wilson, & Chin, 2008):

1. *Information-sharing*: The bidirectional exchange of information between patients and their physicians about symptoms, diagnoses and lifestyle issues relevant to choosing a treatment plan. Patients feel empowered to “tell their story” and have their concerns validated, and physicians provide information using “layman's terms” and in ways that promote patient understanding.
2. *Deliberation/Physician recommendation*: Physician recommendations for treatment plans are grounded in full disclosure of all treatment options. Ideally, patient preferences for treatment are elicited and discussed.
3. *Decision-making*: Patients and physicians arrive at a treatment plan. The process has been conceptualized as a joint endeavor that results in mutual agreement about the plan of care. However, some patients who want a shared role in decision-making may exercise their decisions behaviorally (i.e. adhering or non-adhering to physician recommendations).

We purposely focused on the perceptions of African-American diabetes patients for several reasons. First, learning about the lens through which African-American *patients* view race and SDM can better inform efforts to address communication disparities in ways that are tailored to patient concerns. Second, patients' *perceptions* of what occurs within the clinical setting shapes impressions about their physician (e.g. competence, trustworthiness) and affects future health behaviors (e.g. adherence to treatment plans). Thus, we were more interested in understanding what patients thought about their communication experiences rather than documenting what actually occurred. Lastly, because individualized diabetes care requires ongoing treatment decisions, diabetes may be a disease whose control is particularly sensitive to patient/provider decision-making patterns.

Methods

The methods for this qualitative study have been described in detail elsewhere (Peek, Quinn, Gorawara-Bhat et al., 2008), but are summarized here. We used a phenomenologic research method that included in-depth, individual semi-structured interviews (n=24) and 5 focus groups (n=27) among African-Americans with diabetes. Consistent with guidelines of qualitative methodology, we conducted data collection and analysis simultaneously, and continued enrollment until theme saturation was met (Glaser & Strauss, 1967). A moderator/interviewer experienced in discussing health topics and interpersonal communication was matched to patients on race/ethnicity (Anderson, Barr, Edwards, Funnell, Fitzgerald, & Wisdom, 1996; Jackson, 1991). Each focus group consisted of 5-6 people and lasted approximately 90 minutes. Individual interviews lasted approximately 60 minutes.

Patient recruitment

After receiving approval from our institution's research ethics committee (the Institutional Review Board), study participants were recruited using criterion sampling (Patton, 2002). Eligible patients included African-Americans with diabetes, ≥ 21 years old who had an established relationship with an attending primary care physician at an academic practice in Chicago, Illinois. Patients were randomly identified and up to three attempts were made to contact them via telephone. In addition, culturally-appropriate, low-literacy recruitment materials advertising the study were posted in the clinic waiting room and examination rooms. Study participants received a $15 gift card to a local grocery store as an incentive. Patient sociodemographic and clinical information was collected via self-administered surveys immediately prior to the interviews, and was collected anonymously in the focus groups. Interviews were conducted between September 2006 and February 2007 (response rate of study participation invitations: 67%) and focus groups were conducted between January 2007 and March 2007 (response rate: 57%).

Study Instruments

Topic guides were created with the goal of exploring the following: patient definitions and perceptions of shared decision-making, barriers and facilitators of SDM, and the perceived influence of race/culture on SDM. The guides were informed by constructs of the Charles SDM model (Charles, Gafni, & Whelan, 1997, 1999; Montori, Gafni, & Charles, 2006), the Theory of Planned Behavior (Ajzen, 1991) and the Ecological Model (McLeroy, Bibeau, Steckler, & Glanz, 1988), pilot-tested, and modified in an iterative way.

The guide consisted of a list of open-ended questions and follow-up probes. Queries about race began with the question ‘Do you think that race affects people's relationships with their doctors?’ and followed with probes such as ‘How *exactly* might race affect the relationship?’ and ‘Do you think it matters if the doctor is black or not?’ We also asked for situational examples (i.e. ‘Can you tell me a situation where race played a role [either good or bad] in communicating with the doctor?'), comparative impressions (e.g. 'Do you think it's easier, harder, or the same for blacks to talk with their doctors compared to whites?' and 'Do you think that doctors treat African-American patients, in general, the same, better, or worse than white patients?'), and SDM barriers and facilitators (e.g. What suggestions would you give to African-Americans who are having trouble 'speaking up' to their doctors?).

Data Analysis

Individual interviews and focus groups were audio-taped, transcribed verbatim and imported into Atlas.ti 4.2 software. A team of five investigators with experience in medicine, public health, and psychology independently reviewed and coded the first transcript, met to discuss codes, and created uniform coding guidelines. Subsequently, each transcript was independently coded by two randomly assigned reviewers who then met to discuss coding and address discrepancies. Remaining differences were resolved by the entire group. A codebook was developed using an iterative process where modifications were made to the codes, themes, and concepts that arose from new transcripts (Morgan, 1997). The focus groups were subsequently coded in a similar fashion and analyzed separately from the in-depth interviews for additional codes and themes. Related themes from the analysis were used to develop a conceptual model for understanding the relationship between race and shared decision-making.

Results

Patient characteristics

The majority of study participants were female (82%) and approximately half were 40 to 65 years old (Table). Sixty percent of study participants had completed at least "some college", nearly half the study participants were retired and approximately half had private insurance. No statistically significant demographic differences existed between participants in the in-depth interviews and the focus groups, although participants in the in-depth interviews tended to be older (mean age 66 years vs. 59 years). The average duration of diabetes was 14 years.

Emergent Themes

Participants had a variety of views regarding the perceived relevance of race to shared decision-making and the attributed source of potential race-related communication problems (i.e. patient, physician or socioeconomic). However, dominant themes and patterns emerged within each interview type (in-depth interviews or focus groups) about race and SDM. Whereas the majority of the in-depth interview participants reported that race did not play an important role in patient/provider communication, participants in the focus groups perceived race as a significant factor in such communication. Detailed themes that emerged using each methodology are discussed below.

In-depth Interviews

Relevance of Race—The majority of participants in the in-depth interviews (85%) reported that race did not influence patient/provider communication or shared decision-making. Many participants framed their comments in terms of what *should* occur in an ideal relationship between patients and their physicians, rather than what actually does occur.

> "They are doctors… if they are doctors to take care or soothe whatever the problem is, then it doesn't make a difference who [the patient] is—black or white." (80 year old woman with 3 co-morbid illnesses)

None of the participants reported personally experiencing discrimination or other negative race-related encounters, although most acknowledged that they had "heard about such things", either through their own social networks or "the media".

> "Well, we are told that we're stereotyped and so forth, but I have not had any problem with that…I have heard that we are treated differently, but I haven't found that to be true." (61 year old woman with 1 comorbid illness)

Several participants ascribed their successful communication patterns to self-efficacy or their own beliefs (e.g. lack of prejudice) and actions (e.g. their use of prayer to facilitate provider communication).

> "I don't know about what other African-Americans do, but I always find it easy to talk to my doctor. I have always found it easy to talk to my doctor about anything." (self-efficacy) (74 year old woman with 3 co-morbid illnesses)

> "Well I'm not prejudice, so I don't believe that the white doctors are any different from the black doctors. I think the white doctors only want to perfect their skills." (patient beliefs) (77 year old woman with 2 co-morbid illnesses)

Mechanisms for Race Influencing Shared Decision-Making—Although no one reported having negative communication experiences due to race, most participants had "heard about" such occurrences. Participants most commonly attributed such communication disparities to patient characteristics and actions (50% of participants), whereas physician characteristics and actions (25% of participants) and socioeconomic factors (25% of participants) were mentioned less often.

Reported patient-related characteristics and actions included knowledge (low educational attainment, limited health knowledge, inadequate health literacy), attitudes (negative attitudes towards white providers), beliefs (mistrust of physicians and healthcare systems, internalized racism and physician deference), behaviors (poor "presentation" of themselves [e.g. appearing disheveled, not "speaking well"], and limited participation in health-promoting behaviors).

> "Attitude plays a lot with some [African-Americans]. Some of them go to the doctor and they always have a [negative] attitude. That's not the way to be when you go in to see a doctor. You should always have a pleasing attitude." (patient attitudes) (74 year old woman with 3 co-morbid illnesses)

> "I think it's harder for African-Americans, because African-Americans don't like to communicate with authority. That's what kills us. We feel like if you are a doctor or a lawyer, a policeman or whatever else professional, that they are superior." (patient beliefs) (66 year old man with no co-morbid illnesses)

Instead of bias or discrimination, physician-related factors related to race were often framed in terms of cultural discordance, which we define here as cultural differences perceived as problematic in nature.

> "I think [white physicians] get more irritated with [African-American patients] because a lot of us were raised in the South and you eat all kinds of stuff. And I think they feel like 'if they leave that pig and all that stuff alone, [African-Americans] would be a lot better off.' But that is kind of hard for some of us to do, you know." (50 year old woman with 2 co-morbid illnesses)

Socioeconomic factors, primarily related to insurance status, were believed to contribute to communication disparities.

> "When you don't really have nothing like good insurance, it's hard [to speak up to your doctor]…I think it's all about the insurance, but I can only speak for myself." (47 year old woman with 2 co-morbid illnesses)

Influence of Race on Shared Decision-Making—Participants described how race-related issues might affect patient-level SDM behaviors among African-Americans in the following ways: being less forthcoming about their symptoms and/or health concerns (information-sharing), less likely to speak-up and question the authority of the physician (deliberation/physician recommendations), and less likely to adhere to treatment plans (decision-making).

> “There are very few African-Americans that would question the treatment that they get…” (deliberation/physician recommendations) (66 year old man with no co-morbid illnesses)

> “Some [African-Americans] still don't believe in doctors…I have a neighbor and she goes to the doctor, and when she gets medication she throws it in the garbage can.” (decision-making) (74 year old woman with 2 co-morbid illnesses)

Focus Groups

Relevance of Race—The importance of race in patient/provider communication was raised by participants in each focus group, who described the negative influence of race and shared stories of unpleasant communication experiences that were attributed to race.

> “Race does absolutely—to me—play a part in it… [White physicians] talk to you different if you're black.”

Mechanisms for Race Influencing Shared Decision-Making—Focus group participants primarily attributed communication disparities to physician-related factors, with patient-related factors and socioeconomic factors comprising the rest. Physician-related factors were grounded in issues of stereotypes/bias and cultural discordance.

> “[White] doctors come from a whole ‘nother world. They don't come from where [African-Americans] come from. So they don't know how to communicate with us.” (cultural discordance)

> “The thing that gets to me is when a doctor comes in the room and acts like, because I am black, that I am not smart enough to understand the test that he took or what's going on with the results of the test he took. So I think that's the thing that messes with me the most.” (stereotypes/bias)

Cultural discordance was also discussed within the context of foreign-born physicians

> “You have doctors from Asia and India. I think sometimes there is a language problem. Well, with the accent in English, I think there may be some difficulty. I want to say cultural barriers. I think a foreign doctor doesn't know much about blacks in the U.S. or black culture…Sometimes the patient will say, ‘I tried to explain it to the doctor and he just didn't understand me. He just did his own thing.’”

Of note, participants did not report experiencing discrimination or race-related SDM barriers with African-American physicians. Moreover, several patients reported better communication experiences with African-American doctors and expressed preferences for same-race physicians.

> “I think that's why a lot of women early on went to Dr. X… because he was black. I think it's just a fact of life that you feel more comfortable when you with some one of your own race.”

Patient factors were reported, but were a minor theme within the focus groups. Similar to individual interviews, focus group patients indicated that this could be related to African-

American patients' communication with their doctors. Although mentioned less often, socioeconomic status was believed to play a role.

> “As I see it, prejudice exists everywhere… you look at your healthcare. They are going to look at whether this person is able to pay. That's prejudice to me.”

Influence of Race on Shared Decision-Making—Focus group participants described how race-related issues might affect physician-level SDM behaviors including: being less likely to provide information to patients (e.g. medical explanations or test results) and less likely to listen (information-sharing), being more likely to be domineering and “talk down to” patients (deliberation/physician recommendations), and being less likely to consider patient preferences for treatment plans (decision-making) for African-American patients in comparison to whites.

> “If you go in the room, they just talk right at the patient because they are black. But [as a nurse] when I follow the doctor to another room, they have a different approach, and they're listening to the patient and have a warmer approach and warmer demeanor, and the patient is white. In this room, he would take longer and talked to the patients 15 minutes, but in the other room, he gave 60 seconds to a minute and a half…I see this at the bedside and the patients complain to me—‘I don't like the doctor.’” (information-sharing, deliberation/physician recommendations)

> “[My mother] always said ‘the doctors did not tell me the things that would happen to me’ and I only wondered in my own mind whether that would have been a race thing. Maybe they assumed that she would not understand and we should just ‘do this, do that, take this, and take that’ without a reason why. But my mother was an intelligent woman.” (information-sharing, deliberation/physician recommendations, and decision-making)

Discussion

Participants described race-related issues that may affect patient and physician communicating patterns, and be a barrier to active patient involvement in shared decision-making. Although a range of viewpoints were expressed in both focus groups and in-depth interviews, different themes predominated in these two settings. Within the in-depth interviews, patients were more likely to report that race does not influence patient/provider communication, and among those stating that race may affect communication, patient factors (e.g. limited health knowledge, “bad attitudes” and internalized racism) were thought to be barriers to SDM. No one reported experiencing negative race-related communication encounters or discrimination (although many reported hearing about such occurrences), and most believed that their self-efficacy and communication style accounted for their success at shared decision-making.

In contrast, the majority of patients in the focus groups indicated that race *does* influence patient/physician communication and shared decision-making, and primarily described physician factors (e.g. discrimination and cultural discordance) as the origin of communication disparities. Within every focus group, participants discussed negative communication encounters between white physicians and themselves, family members and/or close friends that they attributed to race.

The reasons for the difference in the predominance of themes between the focus groups and the in-depth interviews are unclear, but likely reflect an array of complex sociopolitical and interpersonal dynamics. First, the differential dynamics of one-on-one versus group encounters could have played a significant role (Lewin & Gullickson, 1997). Despite the use of a race-concordant interviewer and assurances of confidentiality, participants in the in-depth interviews may have felt uncomfortable discussing topics potentially portraying their physician unfavorably, particularly with a researcher affiliated with the health system in which they received their care. In such settings, participants may have felt more compelled to conform to societal norms about patient perceptions of care (Ajzen & Fishbein, 1980). In contrast, focus group participants may have felt more anonymous and more empowered, within a group of persons with similar backgrounds, to speak more openly about healthcare experiences, particularly after someone else had “normalized” and validated perceptions of discrimination within the group (Kitzinger, 1994; Morgan, 1995).

Second, our findings may be interpreted in light of Attribution Theory, wherein people explain, or attribute, their own and others' behaviors in ways that help maintain a positive self-image (Bem, 1972). Persons who have negative experiences are likely to assign external causation (i.e. environmental factors), and persons with positive experiences are likely to assign an internal causation (i.e. personal attributes) (Bem, 1972; Jones & Davis, 1965; Kelley, 1967). We found that persons who denied having negative communication experiences usually attributed their successful interactions to their own self-efficacy, and often attributed negative communication encounters of others to patient-related factors. Similarly, persons who reported negative race-related communication experiences (all of which were reported within focus groups) were usually persons who attributed communication disparities externally to physician-related factors such as discrimination. This external attribution may have been reinforced by group dynamics wherein group norms prohibit the attribution of responsibility to a given member of the group.

Finally, differences in ages between interview and focus group participants may partially explain our findings. Participants in the focus groups were somewhat younger than those in the in-depth interviews. Previous studies have shown that African- Americans that grew up during the civil rights era have more racial centrality/group identification than African-Americans born prior to World War II (Jackson, 1987). Researchers have shown that racial centrality/group identification is positively associated with reports of perceived discrimination, and thus, generational differences may account for some of the higher reporting of negative communication experiences and discrimination within the focus groups (Sellers & Shelton, 2003).

Regardless of the reasons for the differential predominance of themes between the focus groups and the in-depth interviews, our participants identified a range of patient and physician-related factors that may lower the quality of patient/physician communication and be a barrier to shared decision-making between African-American patients and their physicians. Many participants perceived these race-related communication barriers as being rooted in issues of discrimination, cultural discordance and internalized racism.

In order to fully understand the relationship between race and shared decision-making, it is important to place it within the larger context of race and health within the U.S. Jones developed a framework for understanding how race and racism contribute to health disparities (Jones, 2000). This framework consists of three levels of racism—institutionalized, personally-mediated, and internalized racism (Jones, 2000). Institutionalized racism, defined as “differential access to the goods, service and opportunities of society by race” (Jones, 2000), has had manifestations within the field of medicine that include unethical experimentation (Gamble, 1997; Washington, 2006), disparities in healthcare (Hasnain-Wynia, Baker, Nerenz, Feinglass, Beal, Landrum et al., 2007; Schneider, Zaslavsky, & Epstein, 2002; Smedley, Stith, & Nelson, 2002), and unequal access to resources such as health insurance (Doty & Holmgren, 2004; Shi, 2001). Institutionalized racism affects African-Americans' expectations about the quality of care they will receive from clinicians and health systems (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Jacobs, Rolle, Ferrans et al., 2006). Participants in this study noted that differential access to resources such as health insurance and income directly influenced the ability of African-Americans to participate fully in shared decision-making.

It is the other two levels of racism— personally-mediated and internalized— that are particularly relevant to the findings in this study. Internalized racism, defined as “acceptance by members of the stigmatized race of negative messages about their own abilities and intrinsic worth” (Jones, 2000) was reflected in the in-depth individual interviews, where participants perceived that deficient characteristics of other African-Americans (e.g. not “speaking well” or having limited health knowledge) were the reason for communication disparities and less shared decision-making between African-American patients and their physicians.

In contrast to the in-depth interviews, within the focus groups, personally-mediated racism, defined as “prejudice [differential assumptions about the abilities, motives and intentions of others according to their race] and discrimination [differential actions towards others according to their race]” (Jones, 2000), was a prominent theme, and participants disproportionately attributed communication disparities to physician-related factors such as discrimination. A growing body of literature documents the use of negative stereotypes about African-American patients by physicians and healthcare disparities that may result from such implicit bias (Bogart, Kelly, Catz, & Sosman, 2000; Finucane & Carrese, 1990; Green, Carney, Pallin, Ngo, Raymond, Iezzoni et al., 2007; Rathore, Lenert, Weinfurt, Tinoco, Taleghani, Harless et al., 2000; van Ryn & Burke, 2000; van Ryn, Hanan, Burke, & Besculides, 1999), and the clinical encounter may create conditions that heighten the use of stereotypes and unconscious bias. Situations with time pressure, high cognitive demand, limited resources and uncertainty (all found in clinical settings) increase the likelihood of using cognitive shortcuts (e.g. stereotypes) to make decisions (Hamilton, 1981). The most potent forms of discrimination currently experienced by African-Americans are the subtle and unconscious forms of discrimination experienced regularly (Banks, Kohn-Wood, & Spencer, 2006; Harrell, 2000).

We found that participants primarily discussed race-related communication problems within the context of white physicians, although racially unmatched relationships with foreign-born Asian and Indian physicians were reported as particularly problematic. No one in our study reported race-related communication barriers (e.g. discrimination) from African-American physicians. This is an important finding because there is literature suggesting that African-Americans may anticipate and/or report discrimination from same-race physicians in addition to different-race physicians (LaVeist, Rolley, & Diala, 2003; Malat & Hamilton, 2006).

Thus, the lingering vestiges of racism—institutional, internalized and personally-mediated—on both African-Americans and whites, both patients and physicians, may have the potential to influence patient/physician communication and shared decision-making. Within each SDM domain (information-sharing, deliberation/physician recommendations, and decision-making), participants identified areas in which race may have a negative influence.

Within the information-sharing domain (where patients and physicians discuss symptoms, diagnoses and lifestyle issues), participants felt that African-American patients may be less likely to share information with their providers, particularly about health behaviors and medication usage, and physicians may be less likely to share information with their African-American patients, including important information about patient's illnesses and the results of diagnostic tests. Participants also noted that physicians may be less likely to actively and patiently listen to African-American patients in comparison to whites. Our findings are particularly important in light of a previous paper where we reported that information-sharing may be the most important SDM domain to African-Americans, and that the need to “tell their story and be heard” is a crucial experience for this population (Peek, Quinn, Gorawara-Bhat et al., 2008).

Within the 'deliberation/physician recommendation' domain (which focuses on exploring treatment options), participants believed that physicians may be less likely to review treatment options with African-American patients (versus whites), and described how African-Americans may be less willing to "speak up" to their doctors and question physician treatment recommendations because of an exaggerated deference to physicians rooted in internalized racism.

Finally, within the decision-making domain, participants believed that physicians were more likely to be domineering about treatment decisions and less likely to share in the decision-making process with African-American patients. Study participants also described patient-related factors. We previously reported that African-American diabetes patients conceptualize the decision-making so that treatment "noncompliance" was as a viable means of exerting control over treatment decisions and actively participating in their own care (Peek, Quinn, Gorawara-Bhat et al., 2008). In this study, we found that non-adherence may be driven by racial dynamics such as physician mistrust and low self-efficacy to "stand up" to authority figures such as physicians. The phenomenon of verbally agreeing to treatment (e.g. taking insulin) but being non-adherent may be partially explained by the African-American adaptation of presenting one identity to whites (oftentimes a deferential one) and a different identity at home (that may disregard the opinions of whites). This adaptation has its origins in slavery and legalized segregation, which allowed African-Americans to maintain a positive sense of self, exert control over their lives and communities, and avoid physical harm (Pittinsky, Shih, & Ambady, 1999; Banks, Kohn-Wood, & Spencer, 2006; Bogle, 1992; Blassingame, 1979).

In summary, our research suggests that all aspects of shared decision-making— information-sharing, deliberation/physician recommendations, and decision-making— have the potential to be negatively influenced by race, through mechanisms of cultural discordance, patient beliefs arising from internalized racism, and unconscious stereotyping/bias (personally-mediated racism). Such influences serve to exacerbate the inherent power imbalance that exists between patients and their physicians.

This study has several limitations. First, it took place in an urban academic medical center within the midwest region of the United States; the majority of our patients were women and nearly half of patients were retired. As such, our findings may not be generalizable to all African-Americans with diabetes. Second, this research utilized a purposeful sample of patients. Consequently, patients who had particularly strong and/or negative communication experiences with their physicians may have decided to participate in the study at higher rates (in order to express these strong emotions) or at lower rates (to avoid re-experiencing unpleasant encounters) than other patients. And finally, this study did not specifically explore gender, education, age, income, diabetes severity/illness status, or other sociodemographic variables that may influence patient/physician communication patterns. Because race interacts with many of these variables in a variety of settings and social contexts, it is likely that such interplay also occurs within shared decision-making. However, our goal of this study was to focus on the complex issue of race and the various ways that it may influence shared decision-making patterns between patients and physicians. Future studies should build upon this work and explore how race, and its influences, may interact with and be affected by other social variables within the setting of shared decision-making.

Our study has several strengths. First, we were able to obtain in-depth, rich information about a phenomenon that is challenging to explore—the perceived influence of race and racism on communication patterns between patients and physicians. Second, our study utilized a multi-method approach that enhanced our ability to arrive at valid conclusions.

This study suggests that race-related barriers may exist to shared decision-making between African-American patients and their physicians. Finding innovative ways to address such communication barriers and enhance SDM among African-Americans is an important area of research. Because barriers to shared decision-making may exist for patients and providers alike (Peek, Wilson, Gorawara-Bhat, Odoms-Young, Quinn, & Chin, 2009), communication strategies should be developed for both groups. Extending cultural competency training and general communication training for physicians to address potential race-related barriers to SDM has the potential to enhance shared decision-making among African-Americans. While patient communication interventions can be effective, only one study has examined the efficacy of such an intervention among African-Americans and it had no demonstrable effect (although it increased patient communication among whites), a finding the authors attribute to the intervention's lack of cultural appropriateness (Greenfield, Kaplan, Ware, Yano, & Frank, 1988; Post, Cegala, & Marinelli, 2001). Systematic reviews and meta-analyses of diabetes interventions indicate that culturally-tailoring interventions and incorporating behavioral and pyschosocial strategies (versus information transfer alone) have the potential for greater effectiveness (Peek, Cargill, & Huang, 2007; Peyrot, 1999; Anderson, Funnell, Butler, Arnold, Fitzgerald, & Feste, 1995; Brown, 1999). A recent study reported an increase in diabetes self-efficacy among Hispanic Americans when family members were used to support communication efforts with physicians (Coffman, 2008). Thus, culturally-tailored communication training for patients may be an effective strategy for increasing SDM among African-Americans with diabetes, particularly if it incorporates patient beliefs and cultural norms, and addresses potential issues of internalized racism.

Acknowledgments

This research was supported by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Diabetes Research and Training Center (DRTC) (P60 DK20595) and a DRTC Pilot and Feasibility Grant (P60 DK20595). Dr. Peek is supported by the Robert Wood Johnson Foundation (RWJF) Harold Amos Medical Faculty Development program and the Mentored Patient-Oriented Career Development Award of the National Institute of Diabetes and Digestive and Kidney Diseases (K23 DK075006-01). Support for Dr. Chin is provided by a Midcareer Investigator Award in Patient-Oriented Research from the NIDDK (K24 DK071933-01). The funding sources had no role in the design and conduct of the study; collection, management, analysis, or interpretation of the data; and preparation, review, or approval of the manuscript for publication. Dr. Peek had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

References

Adams RJ, Smith BJ, Ruffin RE. Impact of the physician's participatory style in asthma outcomes and patient satisfaction. Ann Allergy Asthma Immunol 2001;86(3):263–271. [PubMed: 11289322]

Ajzen, I.; Fishbein, M. Understanding attitudes and predicting social behavior. Englewood Cliffs, N.J.: Prentice-Hall; 1980.

Anderson RM, Barr PA, Edwards GJ, Funnell MM, Fitzgerald JT, Wisdom K. Using focus groups to identify psychosocial issues of urban black individuals with diabetes. Diabetes Educ 1996;22(1):28–33. [PubMed: 8697953]

Aubert RE, Herman WH, Waters J, Moore W, Sutton D, Peterson BL, Bailey CM, Koplan JP. Nurse case management to improve glycemic control in diabetic patients in a health maintenance organization. A randomized, controlled trial. Ann Intern Med 1998;129(8):605–612. [PubMed: 9786807]

Banks KH, Kohn-Wood LP, Spencer M. An examination of the African American experience of everyday discrimination and symptoms of psychological distress. Community Ment Health J 2006;42(6):555–570. [PubMed: 16897412]

Bem, D. Self-perception theory. In: Berkowitz, L., editor. Advances in Experimental Social Psychology. New York: Academic Press; 1972.

Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical decision making: a review of published surveys. Behav Med 1998;24(2):81–88. [PubMed: 9695899]

Bogart LM, Kelly JA, Catz SL, Sosman JM. Impact of medical and nonmedical factors on physician decision making for HIV/AIDS antiretroviral treatment. J Acquir Immune Defic Syndr 2000;23(5): 396–404. [PubMed: 10866232]

Bonds DE, Zaccaro DJ, Karter AJ, Selby JV, Saad M, Goff DC Jr. Ethnic and racial differences in diabetes care: The Insulin Resistance Atherosclerosis Study. Diabetes Care 2003;26(4):1040–1046. [PubMed: 12663570]

Boulware LE, Cooper LA, Ratner LE, LaVeist TA, Powe NR. Race and trust in the health care system. Public Health Rep 2003;118(4):358–365. [PubMed: 12815085]

Brancati FL, Kao WH, Folsom AR, Watson RL, Szklo M. Incident type 2 diabetes mellitus in African American and white adults: the Atherosclerosis Risk in Communities Study. Jama 2000;283(17): 2253–2259. [PubMed: 10807384]

Caravalho JY, Saylor CR. An evaluation of a nurse case-managed program for children with diabetes. Pediatr Nurs 2000;26(3):296–300. 328. [PubMed: 12026393]

Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med 1997;44(5):681–692. [PubMed: 9032835]

Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Soc Sci Med 1999;49(5):651–661. [PubMed: 10452420]

Cooper-Patrick L, Gallo JJ, Gonzales JJ, Vu HT, Powe NR, Nelson C, Ford DE. Race, gender, and partnership in the patient-physician relationship. Jama 1999;282(6):583–589. [PubMed: 10450723]

Cooper LA, Roter DL, Johnson RL, Ford DE, Steinwachs DM, Powe NR. Patient-centered communication, ratings of care, and concordance of patient and physician race. Ann Intern Med 2003;139(11):907–915. [PubMed: 14644893]

Davidson JE, Powers K, Hedayat KM, Tieszen M, Kon AA, Shepard E, Spuhler V, Todres ID, Levy M, Barr J, Ghandi R, Hirsch G, Armstrong D. Clinical practice guidelines for support of the family in the patient-centered intensive care unit: American College of Critical Care Medicine Task Force 2004-2005. Crit Care Med 2007;35(2):605–622. [PubMed: 17205007]

Doty MM, Holmgren AL. Unequal access: insurance instability among low-income workers and minorities. Issue Brief (Commonw Fund) 2004;(729):1–6.

Finucane TE, Carrese JA. Racial bias in presentation of cases. J Gen Intern Med 1990;5(2):120–121. [PubMed: 2313403]

Gamble VN. Under the shadow of Tuskegee: African Americans and health care. Am J Public Health 1997;87(11):1773–1778. [PubMed: 9366634]

Gary TL, McGuire M, McCauley J, Brancati FL. Racial comparisons of health care and glycemic control for African American and white diabetic adults in an urban managed care organization. Dis Manag 2004;7(1):25–34. [PubMed: 15035831]

Glaser, BG.; Strauss, AL. The discovery of grounded theory; strategies for qualitative research. Chicago: Aldine Pub. Co; 1967. p. x-271.

Green AR, Carney DR, Pallin DJ, Ngo LH, Raymond KL, Iezzoni LI, Banaji MR. Implicit bias among physicians and its prediction of thrombolysis decisions for black and white patients. J Gen Intern Med 2007;22(9):1231–1238. [PubMed: 17594129]

Greenfield S, Kaplan S, Ware JE Jr. Expanding patient involvement in care. Effects on patient outcomes. Ann Intern Med 1985;102(4):520–528. [PubMed: 3977198]

Greenfield S, Kaplan SH, Ware JE Jr, Yano EM, Frank HJ. Patients' participation in medical care: effects on blood sugar control and quality of life in diabetes. J Gen Intern Med 1988;3(5):448–457. [PubMed: 3049968]

Hamilton, DL. Cognitive processes in stereotyping and intergroup behavior. Hillsdale, N.J.: L. Erlbaum Associates; 1981.

Harrell SP. A multidimensional conceptualization of racism-related stress: implications for the well-being of people of color. Am J Orthopsychiatry 2000;70(1):42–57. [PubMed: 10702849]

Harris MI. Racial and ethnic differences in health care access and health outcomes for adults with type 2 diabetes. Diabetes Care 2001;24(3):454–459. [PubMed: 11289467]

Hasnain-Wynia R, Baker DW, Nerenz D, Feinglass J, Beal AC, Landrum MB, Behal R, Weissman JS. Disparities in health care are driven by where minority patients seek care: examination of the hospital quality alliance measures. Arch Intern Med 2007;167(12):1233–1239. [PubMed: 17592095]

Heisler M, Smith DM, Hayward RA, Krein SL, Kerr EA. Racial disparities in diabetes care processes, outcomes, and treatment intensity. Med Care 2003;41(11):1221–1232. [PubMed: 14583685]

Jackson BO. The effects of racial group consciousness on political mobilization in American cities. Western Political Quarterly 1987;40:631–646.

Jackson, JS. Methodologic approach. In: Jackson, JS., editor. Life in Black America. Newbury Park, CA: Sage; 1991.

Jacobs EA, Rolle I, Ferrans CE, Whitaker EE, Warnecke RB. Understanding African Americans' views of the trustworthiness of physicians. J Gen Intern Med 2006;21(6):642–647. [PubMed: 16808750]

Jha AK, Varosy PD, Kanaya AM, Hunninghake DB, Hlatky MA, Waters DD, Furberg CD, Shlipak MG. Differences in medical care and disease outcomes among black and white women with heart disease. Circulation 2003;108(9):1089–1094. [PubMed: 12939228]

Johnson RL, Roter D, Powe NR, Cooper LA. Patient race/ethnicity and quality of patient-physician communication during medical visits. Am J Public Health 2004;94(12):2084–2090. [PubMed: 15569958]

Jones CP. Levels of racism: a theoretic framework and a gardener's tale. Am J Public Health 2000;90(8): 1212–1215. [PubMed: 10936998]

Jones, EE.; Davis, KE. From acts to dispositions: The attribution process in person perception. In: Berkowitz, L., editor. Advances in experimental social psychology. New York: Academic Press; 1965. p. 219-266.

Kelley, HH. Attribution theory in social psychology. In: Levine, D., editor. Nebraska Symposium on Motivation. Lincoln, NE: University of Nebraska Press; 1967. p. 192-238.

Kitzinger J. The methodology of focus groups: The importance of interaction between research participants. Sociology of Health & Illness 1994;16:103–121.

Larson EB, Fihn SD, Kirk LM, Levinson W, Loge RV, Reynolds E, Sandy L, Schroeder S, Wenger N, Williams M. The future of general internal medicine. Report and recommendations from the Society of General Internal Medicine (SGIM) Task Force on the Domain of General Internal Medicine. J Gen Intern Med 2004;19(1):69–77. [PubMed: 14748863]

Lerman CE, Brody DS, Caputo GC, Smith DG, Lazaro CG, Wolfson HG. Patients' Perceived Involvement in Care Scale: relationship to attitudes about illness and medical care. J Gen Intern Med 1990;5(1): 29–33. [PubMed: 2299426]

Levinson W, Hudak PL, Feldman JJ, Frankel RM, Kuby A, Bereknyei S, Braddock C 3rd. “It's not what you say …”: racial disparities in communication between orthopedic surgeons and patients. Med Care 2008;46(4):410–416. [PubMed: 18362821]

Lewin K, Gullickson T. Resolving social conflicts: Field theory in Social Science. PsychCRITIQUES 1997;42(8):756.

McBean AM, Li S, Gilbertson DT, Collins AJ. Differences in diabetes prevalence, incidence, and mortality among the elderly of four racial/ethnic groups: whites, blacks, hispanics, and asians. Diabetes Care 2004;27(10):2317–2324. [PubMed: 15451894]

Michel DM, Moss AH. Communicating prognosis in the dialysis consent process: a patient-centered, guideline-supported approach. Adv Chronic Kidney Dis 2005;12(2):196–201. [PubMed: 15822055]

Montori VM, Gafni A, Charles C. A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. Health Expect 2006;9(1):25–36. [PubMed: 16436159]

Morgan DL. Why things (sometimes) go wrong in focus groups. Qualitative Health Research 1995;5:516–523.

Morgan, DL. Focus groups as qualitative research. Thousand Oaks, Calif.: Sage Publications; 1997.

Nelson K, Norris K, Mangione CM. Disparities in the diagnosis and pharmacologic treatment of high serum cholesterol by race and ethnicity: data from the Third National Health and Nutrition Examination Survey. Arch Intern Med 2002;162(8):929–935. [PubMed: 11966345]

Oliver MN, Goodwin MA, Gotler RS, Gregory PM, Stange KC. Time use in clinical encounters: are African-American patients treated differently? J Natl Med Assoc 2001;93(10):380–385. [PubMed: 11688918]

Patton, MQ. Qualitative research & evaluation methods. 3rd. Thousand Oaks, CA: Sage; 2002.

Peek ME, Quinn MT, Gorawara-Bhat R, Odoms-Young A, Wilson SC, Chin MH. How is shared decision-making defined among African-Americans with diabetes? Patient Educ Couns 2008;72(3):450–458. [PubMed: 18684581]

Purdie-Vaughns V, Steele CM, Davies PG, Ditlmann R, Crosby JR. Social identity contingencies: how diversity cues signal threat or safety for African Americans in mainstream institutions. J Pers Soc Psychol 2008;94(4):615–630. [PubMed: 18361675]

Rathore SS, Lenert LA, Weinfurt KP, Tinoco A, Taleghani CK, Harless W, Schulman KA. The effects of patient sex and race on medical students' ratings of quality of life. Am J Med 2000;108(7):561–566. [PubMed: 10806285]

Richardson, WC.; Berwick, DM.; Bisgard, JD.; Bristow, LR.; Buck, CR.; Cassel, CK.; Chassin, MR.; Coye, MJ.; Detmer, DE.; Grossman, JH.; James, B.; Lawrence, DM.; Leape, LL.; Levin, A.; Robinson-Beale, R.; Scherger, JE.; Southam, A.; Wakefield, M.; Warden, GL. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, D.C.: Institute of Medicine; 2001.

Schneider EC, Zaslavsky AM, Epstein AM. Racial disparities in the quality of care for enrollees in medicare managed care. Jama 2002;287(10):1288–1294. [PubMed: 11886320]

Sellers RM, Shelton JN. The role of racial identity in perceived racial discrimination. J Pers Soc Psychol 2003;84(5):1079–1092. [PubMed: 12757150]

Sheridan SL, Harris RP, Woolf SH. Shared decision making about screening and chemoprevention. a suggested approach from the U.S. Preventive Services Task Force. Am J Prev Med 2004;26(1):56–66. [PubMed: 14700714]

Shi L. The convergence of vulnerable characteristics and health insurance in the US. Soc Sci Med 2001;53 (4):519–529. [PubMed: 11459401]

Smedley, BD.; Stith, SY.; Nelson, AR., editors. Institute of Medicine. Washington, D.C.: National Academies Press; 2002. Unequal treatment: confronting racial and ethnic disparities in health care.

Stewart M, Brown JB, Donner A, McWhinney IR, Oates J, Weston WW, Jordan J. The impact of patient-centered care on outcomes. J Fam Pract 2000;49(9):796–804. [PubMed: 11032203]

Stewart MA. Effective physician-patient communication and health outcomes: a review. Cmaj 1995;152 (9):1423–1433. [PubMed: 7728691]

van der Weijden T, van Veenendaal H, Timmermans D. Shared decision-making in the Netherlands—current state and future perspectives. Z Arztl Fortbild Qualitatssich 2007;101(4):241–246. [PubMed: 17601179]

van Ryn, M.; Hanan, E.; Burke, J.; Besculides, M. An examination of factors associated with physician recommendation for revascularization. Washingtion, DC: American Public Health Association; 1999.

van Ryn M, Burke J. The effect of patient race and socio-economic status on physicians' perceptions of patients. Soc Sci Med 2000;50(6):813–828. [PubMed: 10695979]

Washington, HA. Medical apartheid : the dark history of medical experimentation on Black Americans from colonial times to the present. New York: Doubleday; 2006.

Table

Patient Demographics (n=51)

	In-depth Interviews (n=24)	Focus Groups (n=27)	p-value
Age (mean, yrs)	66	59	0.242
18-39	0	7	
40-54	17	19	
55-64	17	44	
65-74	45	30	
> 75	21	0	
Female gender	83	81	0.16
Marital status			0.22
Single	11	33	
Married/Living as married	42	22	
Separated/Divorced/Widowed	47	45	
Education			0.20
Some high school or less	11	4	
High school graduate	26	41	
Some college	42	33	
College graduate or higher	22	22	
Employment			0.21
Employed	5	22	
Unemployed	26	44	
Retired	68	33	
Income, $			0.22
<15,000	5	33	
15,000-24,999	26	7	
25,000-49,999	26	22	
> 50,000	21	26	
Refused	22	11	
Living Space			0.24
Rent	47	52	
Own	53	44	
Other	0	4	
Insurance			0.09
Uninsured	0	0	
Medicare	4	4	
Medicaid	13	22	
Medicare + Medicaid	21	26	
Private Insurance	29	30	

	In-depth Interviews (n=24)	**Focus Groups (n=27)**	**p-value**
Medicare + Private	33	18	
Years of Diabetes (Average)	14	14	
Medication Regimen			0.29
Lifestyle modification only	21	11	
Oral agents w/o insulin	46	48	
Insulin	12	11	
Oral agents w/ insulin	21	30	
Diabetes Complications			0.24
0	50	37	
1	21	37	
2	25	19	
3+	4	7	
Co-morbid Illnesses			
Cerebrovascular disease	13	4	<0.01
Coronary artery disease	33	7	<0.01
Hypertension	66	74	0.07
Hyperlipidemia	50	44	<0.01
Peripheral vascular disease	25	15	<0.01