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Patient Trust in Physicians and Shared Decision-Making Among African-Americans With Diabetes

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Abstract

This study explores patient trust in physicians and its relationship to shared decision-making (SDM) among African-Americans with diabetes (types 1 and 2). We conducted a series of focus groups (n = 27) and in-depth interviews (n = 24). Topic guides were developed utilizing theoretical constructs. Each interview was audiotaped and transcribed verbatim. Each transcript was independently coded by two randomly assigned members of the research team; codes and themes were identified in an iterative fashion utilizing Atlas.ti software. The mean age of study participants was 62 years and 85% were female. We found that (1) race as a social construct has the potential to influence key domains of patient trust (interpersonal/relationship aspects and medical skills/technical competence), (2) the relationship between patient trust and shared decision-making is bidirectional in nature, and (3) enhancing patient trust may potentially increase or decrease SDM among African-Americans with diabetes. Mistrust of physicians among African-Americans with diabetes may partially be addressed through (1) patient education efforts, (2) physician training in interpersonal skills and cultural competence, and (3) physician efforts to engage patients in SDM. To help enhance patient outcomes among African-Americans with diabetes, physicians might consider incorporating strategies to simultaneously engender their patients' trust and encourage shared decision-making.

Patient trust in physicians and shared decision-making (SDM) are associated with positive patient health outcomes such as adherence to treatment plans, self-reported health status, increased preventive care utilization, and clinical outcomes, such as diabetes control (Parchman, Zeber, & Palmer, 2010; Safran et al., 1998; Thom, Ribisl, Stewart, & Luke, 1999). Shared decision-making has been conceptualized as having three key domains: information-sharing between patients and physicians, deliberation about the pros and cons of treatment choices, and decision-making about a treatment plan that is endorsed by both the patient and the physician (Charles, Gafni, & Whelan, 1997, 1999; Montori, Gafni, & Charles, 2006). African-Americans are less likely to trust their physicians and less likely to experience SDM than are non-Hispanic Whites, both of which may be contributors to disparities in health outcomes (Ashton et al., 2003; Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Kaiser et al., 2010; Levinson et al., 2008; Peek et al., 2010b; Siminoff, Graham, & Gordon, 2006). One study found that African-Americans were 37% less likely to report trusting their physicians than non-Hispanic Whites (Boulware et al., 2003). Mistrust of physicians and health care institutions among African-Americans has been previously explored; many of the underlying reasons are related to the historical legacy of unethical experimentation within the United States, a segregated and underresourced health care system, and prior experiences of overt racism by health care providers (Baker et al., 2008; Washington et al., 2009).

African-Americans report experiencing worse patient/provider communication and SDM measures when interacting with physicians, including less information-sharing, decision-making, respect, responsiveness, listening, supportiveness, and partnership building than their non-Hispanic White peers (Cooper et al., 2003; Cooper-Patrick et al., 1999; Gordon, Street, Sharf, Kelly, & Soucheck, 2006; Johnson, Roter, Powe, & Cooper, 2004; Levinson et al., 2008; Siminoff et al., 2006).

Among the general population, it is known that trust and shared decision-making are interrelated phenomena, although the mechanisms by which they are related are not completely understood (Entwistle, 2004). Kraetschmer et al. (2004) found that "blind trust" by patients toward their physicians is associated with patient preferences for a passive role, low trust is associated with preferred autonomous roles, and moderate amounts of trust are associated with preferences for shared decision-making roles with physicians. For African-Americans, race may impact both patient trust and shared decision-making (Gamble; 1997; Peek, Sayad, & Markwardt, 2008b; Peek et al.,2010a; 2010b; Thom et al., 1999), and as such, the relationship between trust and SDM may be different for this group than for other racial/ethnic groups (Peek et al., 2010b). For example, it is possible that patients' trust in their physicians is not associated with preferences for passive roles among some African-Americans, who, despite trusting their individual physicians, may have residual mistrust of the health care system that limits their ability to relinquish decision-making control.

Previous research exploring the relationship between patient trust and SDM among African-Americans is limited. Enhancing both patient trust and shared decision-making among African-Americans has the potential to improve health outcomes and reduce health disparities, yet many unanswered questions remain. While much research documents that African-Americans disproportionately mistrust physicians (Boulware et al., 2003), it is not known which domains of trust (e.g., values, technical competence) are affected. In addition, little work has explored potential facilitators (including shared decision-making and patient/provider communication) of patient trust among this population (Jacobs, Rolle, Ferrans, Whitaker, & Warnecke, 2006), particularly African-Americans with diabetes. Thus, investigating these key areas—that is, (1) which aspects of patient trust may be negatively affected by race and (2) whether SDM can influence patient trust—is an important endeavor that can help identify potential strategies to improve patient trust among African-Americans.

It is also important to understand whether trust may, in turn, influence decision-making patterns among African-Americans, and this area has also been understudied. While we previously reported that racial mistrust of physicians may be a barrier to SDM among African-Americans (Peek et al., 2009, 2010a), we did not explore whether trust might lead to preferences for passive roles and, consequently, decrease some African-Americans' preferences for shared decision-making. Thus, there is a need to learn more about trust and SDM among African-Americans, particularly how these two domains potentially interact.

We sought to explore these issues among African-Americans with diabetes, a population that disproportionately suffers poor health outcomes from their disease and whose condition may be particularly affected by patient/provider communication and shared decision-making (Montori et al., 2006; Parchman et al., 2010; Peek, Cargill, & Huang, 2007). This study builds upon our prior work exploring shared decision-making among African-Americans with diabetes, including how members of this group define SDM themselves (Peek et al., 2008a; 2009; 2010a), and seeks to address the aforementioned gaps in the existing literature.

Methods

The methods for this qualitative study have been described in detail elsewhere (Peek et al., 2008a). We conducted five focus groups (n = 27) and a series of in-depth, individual semistructured interviews (n = 24) among African-American patients with type 1 and type 2 diabetes. Enrollment continued until theme saturation was reached (Glaser & Strauss, 1967). A moderator/interviewer with experience discussing health and communication issues was matched on race/ethnicity to patients (Anderson et al., 1996). Individual interviews lasted approximately 60 minutes and focus groups lasted approximately 90 minutes.

Participant Recruitment

After receiving approval from the institutional review board (IRB), participants were recruited using criterion sampling (Patton, 2002). Eligible participants included African-American patients with diabetes, >:21 years old, who had an established relationship with an attending primary care physician at an academic internal medicine practice (defined as at least three visits over the preceding 2 years with the same attending) in the Midwest region of the United States. Patients were identified utilizing administrative databases to search for patient visit information and diabetes codes (based on the International Classification of Diseases, 9th Revision, Clinical Modification [ICD-9-CM], codes 250.00–250.91). Up to three attempts were made to contact participants via telephone. In addition, culturally appropriate, low-literacy recruitment materials advertising the study were posted in the clinic. 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. 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 participants consisted exclusively of patients; physicians were not interviewed as part of this study.

Study Instruments

Topic guides were created to explore 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 created utilizing constructs of the Charles SDM model (Charles et al., 1997, 1999; Montori et al., 2006), the theory of planned behavior (TPB) (Azjen & Fishbein, 1991), and the ecological model (EM) (McLeroy, Bibeau, Steckler, & Glanz, 1988), pilot-tested and modified in an iterative way. The Charles model was used to explore patient perceptions of shared decision-making; the TPB and EM were used to investigate

patient willingness to engage in SDM, perceived SDM barriers/facilitators and the impact of race on SDM. In the TPB, behavior is determined by a person's intention to perform it, perceived control (self-efficacy) over performing the behavior, and the weighted relative importance of the behavioral attitudes and subjective norms (Azjen & Fishbein, 1991). The ecological model expands the influences on behavior to include environmental factors such as institutional influences (e.g., institutional racism) and social institutions (McLeroy et al., 1988). Thus, in this analysis, we were interested in learning about normative cultural beliefs and behaviors about shared decision-making among African-Americans (the TPB) and how environmental factors (e.g., perceived health care discrimination) and social relationships (e.g., patient trust) (the EM) may interact with shared decision-making among this population. The EM and TPB models have been used previously to explore choice intentions, consumer behavior, and health-promoting behavior of African-Americans with diabetes (Burnet, Plaut, Courtney, & Chin, 2002).

The resulting moderator guide consisted of a list of open-ended questions and follow-up probes. Trust was not directly asked about in the interviews and focus groups but indirectly through the use of probes (e.g., "How do you think Blacks feel about their doctors in general?" and "How *exactly* might race affect the relationship between African-American patients and their physicians?"). Because patients were asked to talk about all prior health care encounters (vs. only those with their current doctors), we did not document racial concordance/discordance between patients and their entire team of current physicians. However, none of the study participants were in racially concordant relationships with their primary care physicians at the time of the interviews and focus groups.

Data Analysis

Interviews and focus groups were audiotaped, transcribed verbatim, and imported into Atlas.ti 4.2 software (Scientific Software Development, 2000). We utilized a thematic analysis approach to the data (Braun & Clarke, 2006). A team of six investigators with experience in medicine, public health, and psychology independently reviewed and coded the first interview transcript, met to discuss codes, and created uniform coding guidelines. Subsequently, each interview 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). After all in-depth interview transcripts were coded, they were divided equally among the five reviewers for in-depth review and analysis. Summaries of the final themes and concepts were discussed by the entire research group in an iterative manner. These themes formed the basis of the focus group topic guide. The focus groups were subsequently coded in a similar fashion and analyzed separately from the in-depth interviews for additional codes and themes.

Results

Patient Characteristics

The mean age of study participants was 62 years and 85% were female (see Table 1). Sixty percent of study participants had completed at least "some college," 39% had an annual household income of <\$25,000, and approximately half had private insurance. The average duration of diabetes was 14 years, 37% of participants used insulin, 28% had at least two diabetes complications, and 71% had hypertension.

Emergent Themes

Race and trust—Participants described patient trust in physicians as arising from two domains: interpersonal/relationship aspects and medical skills/technical competence, both of which were influenced by race/culture.

Interpersonal/relationship aspects of trust—Physician racial bias and cultural discordance were perceived as negatively impacting the relationship aspects of trust and were reflected in comments such as, "Whatever the treatment is or whatever [the doctor] says, you are thinking he doesn't know what he's talking about, I can't trust him, he doesn't know anything about the Black race." Another said, "The [doctor] came into the room speaking in a very condescending manner—as if we were children. My mother, my brother, my sister and my dad were all in the room ... It was his tone of voice, and it was his mannerisms. As if he didn't want to be there ... And I'm sure that if [we] had been of a different race, [the doctor] probably would have been different." Conversely, interpersonal skills were reported as facilitators of trust. One participant said, "I like my doctor because of his kindness, his concern and his caring spirit, you know. I think he's a marvelous doctor, and I trust him." Honesty was seen as key to the partnership-building needed to foster a trusting relationship. One person said, "I can say that [my doctors] are pretty honest8 with me—that's key. So I trust them."

Medical skills/technical competence aspects of trust—Medical skills/technical competence was the other primary source of trust among study participants. One person noted, "When I saw the results [good health outcomes], I was more confident and my trust in the doctor grew." This domain was also influenced by race, primarily in the context of concerns about unethical experimentation. Another person said, "Do you know about the [Tuskegee] syphilis experiment? Black people, they know about this and they just don't trust doctors. They feel like every time they come to the doctor a White physician wants to experiment on them." Yet another participant noted, "Dr. X, or whoever she was, she must have been experimenting on me because she didn't know what she was doing. She left a big scar on my neck ... I don't want that lady to ever touch me again. I don't like her and I don't trust her."

Participants did report issues of mistrust with the health care system in general, particularly as related to issues of health insurance and health care access. While patients in our study described mistrust of individual physicians, this mistrust did not appear to arise from distrust of the health care system (e.g., institutional policies and procedures that resulted in disparate care for African-Americans). One participant said, "I think that most doctors try to treat the patient the best that there is for his or her condition—I know my doctor does. But a lot of these insurances now wouldn't allow that ...The insurance has a lot to do with the treatment that African-Americans get. Yep, these insurance companies, they are going to give White people better care than the Black ones, most of these companies today."

The influence of shared decision-making on patient trust—Physicians' shared decision-making behaviors were viewed as facilitators of patient trust. Such trust was enhanced when physicians gave patients more information, including test results and general information about their health (the information-sharing domain of SDM), and also when physicians gave details about the pros and cons of various treatment options (the deliberation domain of SDM). One participant said, "I have a lot of confidence in the way he educates me, like I was telling you. He tells me a lot of things that physicians don't usually tell patients; he knows a lot and he teaches me a lot." Another person noted, "[The doctors] explained to us what was happening to him and what he really needed. We trusted those doctors." Participants reported that trust was also enhanced when they felt as though their

physicians encouraged them to share information. Such encouragement was described in nonverbal communication terms such as active listening. For example, one person said, "She would listen and talk to me about decisions and medications. She took time and I felt like I could trust her because she listened and took a lot of time."

Race was perceived as influencing physician SDM behaviors, and subsequently affecting trust. Participants described how implicit racial bias may negatively impact a physician's willingness to engage in SDM activities such as information sharing. For example, one participant said, "Well, I feel that some [physicians] you [as an African-American patient] can't trust because you don't get all of the information that you should have ... Like your overall tests and the advice and all that stuff ... I don't think that they give you the right answers to your tests."

The influence of patient trust on shared decision-making—Interestingly, some participants noted that their level of trust in their physician influenced their decision-making role preferences (passive, shared, and autonomous). They described how patient trust led to the adoption of more shared decision-making preferences and behaviors (from prior autonomous role preferences/behaviors). For example, one participant described the decision to start insulin this way: "It could have gone so bad with a strong personality like mine; I usually want to call all the shots. But I really trusted him, and he was patient and he talked me through it ... So we ultimately decided together that insulin would be the best thing ... and I think that [physician encounter] was one of the best experiences of my life and I respect that he was a good doctor." Trust was seen as a facilitator of SDM by creating a "safe zone" for patients to be honest and to speak up and ask questions. One participant said, "[My doctor] took time and I felt like I could trust her ... now I feel more comfortable talking to her about my health."

Conversely, other participants reported that patient trust allowed them to play a more passive role in the clinical encounter. One participant noted, "I prefer that my doctor tell me what to do. I have a trust issue, but I really trust this doctor, so I'm more comfortable with him just telling me what to do." Similarly, another divulged, "I don't question [my doctor] or talk about my preferences for treatment, because I have full confidence and trust in him."

Discussion

The qualitative findings just described led us to believe that (1) race as a social construct has the potential to influence the two key domains of patient trust (interpersonal/relationship aspects and medical skills/technical competence), as well as shared decision-making behaviors (see Figure 1), (2) the relationship between patient trust and SDM among African-Americans is bidirectional, and (3) increased patient trust may have the potential to either enhance shared decision-making or reduce SDM among African-Americans with diabetes, which has important implications for the health outcomes of this population.

Participants described patient trust as primarily arising from the two already-mentioned domains, which are consistent with current conceptualizations of patient trust, in that there are two key areas, one of values (e.g., respect, honesty, caring) and another of technical competence (Hall, Camacho, Dugan, & Balkrishnan, 2002; Rowe & Calnan, 2006). Our study highlights that key aspects of both domains of patient trust among African-Americans are influenced by race through perceptions of physician bias (e.g., discrimination) and issues that arise from cultural discordance. Our results also lead us to propose that physician mistrust among African-Americans may potentially be reduced through (1) patient education efforts (i.e., demonstration of medical knowledge/skills) and (2) physician training in interpersonal skills and cultural competence. Patient education efforts may be particularly

important for African-Americans, who have disproportionately low health literacy and lower diabetes knowledge (Schillinger et al., 2002; Williams, Baker, Parker, & Nurss, 1998). Further, increasing patients' understanding of their disease process has the potential to enhance shared decision-making (Hall, Roter, & Katz, 1988) as well as patient trust. Enhancing physicians' interpersonal skills may also foster trust among African-American patients, who are more likely than their White peers to rate their physicians' interpersonal skills as low in areas such as respect and supportiveness (Blanchard & Lurie, 2004; Gordon et al., 2006). Honesty was described as an important contributor to relationship building and the development of patient trust, a finding corroborated by Torke, Corbie-Smith, and Branch (2004) in a study of African-Americans and end-of-life care. Cultural competency training for physicians may decrease the perception of cultural discordance among African-Americans that contributes to patient mistrust. Many medical schools have incorporated courses on the patient/provider relationship that include communication, cultural competence, and interpersonal skills (Beach et al., 2005; Hauer, Fernandez, Teherani, Boscardin, & Saba, 2010), which may better equip young physicians to establish rapport, enhance communication quality, and develop trusting relationships (Carrillo, Green, & Betancourt, 1999), even among groups with higher levels of mistrust such as African-Americans (Boulware et al., 2003; Corbie-Smith, Thomas, & St. George, 2002).

We also found that physician SDM behaviors, particularly in the area of information-sharing, can enhance patient trust among African-Americans with diabetes. Because African-Americans may disproportionately have concerns about physicians withholding medical information (Sheppard, Zambrana, & O'Malley, 2004; Torke et al., 2004), discussing clinical conditions and test results in accessible ways has the potential to reduce physician mistrust among African-American patients. Patients in our study reported concerns about physician bias and the subsequent withholding of medical information from African-American patients. In a prior study, we found that being able to "tell one's story" and "be heard" were critical aspects in how African-Americans defined the shared decision-making experience (Peek et al., 2008a). In this study, participants reported that physician support of patient information-sharing can foster trust among African-Americans. Our finding that SDM can enhance patient trust is consistent with the Gordon et al. (2006) study of lung cancer patients, which found that reports of lower communication quality (including informativeness, partnership and supportiveness) among Black patients predicted racial differences (between Blacks and Whites) in postvisit patient trust.

Our results showed that trust and shared decision-making appear to have a bidirectional relationship. In addition to SDM influencing patient trust, participants described how trust may affect decision-making role preferences (i.e., passive, shared, autonomous). Entwistle (2004) theorized that trust may enhance SDM because patients feel safer in engaging in honest discussions with their physicians, but trust may also impair patient contributions to medical decisions and foster a more passive patient role. Our research findings support these theories. We found that within trusting relationships, participants described having a "safe zone" to be honest with their doctor, and to speak up and ask questions. Conversely, participants also described feeling more comfortable relying on physician recommendations and participating less in treatment decisions when they trusted their doctors.

Race appeared to be a key underlying influence in the relationship between patient trust and SDM. Participants' concerns regarding physician bias and cultural discordance affected trust in their physicians as well as their perceptions of physicians' SDM behaviors. Although participants reported some mistrust of the health care system overall, it was not described as impacting their trust with individual physicians or their decision-making role preferences.

Our study has some limitations. First, because this was a qualitative study, we did not quantify the levels of patient trust among our participants (i.e., with the use of a validated survey instrument). Kraetschmer et al. (2004) found that moderate levels of trust were associated with SDM, while high levels of trust ("blind trust") were associated with more passive preferences. Whether these patterns exist among African-Americans is currently unknown. Second, the study took place in an urban academic medical center within the Midwest region of the United States, and the majority of our patients were women. As such, our findings may not be generalized to all African-Americans with diabetes. Third, this research utilized a purposeful sample of patients. Consequently, patients who had particularly strong and/or negative communication experiences with their physicians may have been more likely to participate in the study.

Nonetheless, our study has several strengths. Most importantly, it gives insight into how to enhance trust and reduce mistrust among African-Americans, a population with well-entrenched patterns of patient mistrust that are believed to contribute to health disparities among this group. Second, our study utilized a multimethod approach that enhanced the ability to accurately interpret our data.

Conclusion

In summary, we found that (1) key domains of patient trust and SDM are influenced by race; (2) there appears to be a bidirectional relationship between patient trust and shared decision-making; and (3) increased patient trust may have the potential to either enhance shared decision-making or reduce SDM among African-Americans. Areas of future research include identifying ways to improve patient trust among African-Americans while simultaneously empowering them to play more active roles in the clinical encounter, with the main goal of improving diabetes outcomes in this population. African-Americans' mistrust of physicians may partially be addressed through (1) patient education efforts, (2) physician training in interpersonal skills and cultural competence, and (3) physician efforts to engage patients in the shared decision-making process. Enhancing patient trust may help empower African-American patients to take more active roles in the clinical encounter, but practitioners should be aware that it might lead to more passive patient behaviors. To help enhance patient outcomes among African-Americans with diabetes, physicians might consider incorporating strategies to simultaneously engender their patients' trust and encourage shared decision-making.

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Figure 1. Conceptual model

Table 1 Patient Demographics (n = 51)

Characteristic	Percentage
Age (mean, years)	62
18–39	4
40–54	18
55–64	31
65–74	37
>75	10
Female gender	82
Marital status	
Single	24
Married/living as married	30
Separated/divorced/widowed	46
Education	
Some high school or less	7
High school graduate	35
Some college	36
College graduate or higher	22
Employment	
Employed	15
Unemployed	37
Retired	48
Income, \$	
<15,000	22
15,000-24,999	15
25,000–49,999	24
>;50,000	24
Refused	15
Living space	
Rent	50
Own	48
Other	2
Insurance	
Uninsured	0
Medicare	4
Medicaid	18
Medicare + Medicaid	24
Private insurance	29

Characteristic Percentage Medicare + private 25 Years of diabetes (average) 14 Medication regimen Diet changes 16 Pills/tablets 47 Insulin 11 Pills and insulin 26 Diabetes complications 0 1 2 3+ 6 Co-morbid conditions

8

19

70

47

20

Peek et al.

Stroke

Hypertension

Hyperlipidemia

Coronary artery disease

Peripheral vascular disease

Page 14