BRIEF REPORT

Barriers and Facilitators to Shared Decision-making Among African-Americans with Diabetes

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INTRODUCTION: Shared decision-making (SDM) between patients and their physicians is associated with improved diabetes health outcomes. African-Americans have less SDM than Whites, which may contribute to diabetes racial disparities. To date, there has been little research on SDM among African-Americans.

OBJECTIVE: We explored the barriers and facilitators to SDM among African-Americans with diabetes.

METHODS: Qualitative research design with a phenomenological methodology using in-depth interviews (n=24) and five focus groups (n=27). Each interview/focus group was audio-taped and transcribed verbatim, and coding was conducted using an iterative process. *Participants*: We utilized a purposeful sample of African-American adult patients with diabetes. All patients had insurance and received their care at an academic medical center.

RESULTS: Patients identified multiple SDM barriers/facilitators, including the patient/provider power imbalance that was perceived to be exacerbated by race. Patient-related factors included health literacy, fear/denial, family experiences and self-efficacy. Reported physician-related barriers/facilitators include patient education, validating patient experiences, medical knowledge, accessibility and availability, and interpersonal skills.

DISCUSSION: Barriers/facilitators of SDM exist among African-Americans with diabetes, which can be effectively addressed in the outpatient setting. Primary care physicians, particularly academic internists, may be uniquely situated to address these barriers/facilitators and train future physicians to do so as well.

KEY WORDS: shared decision-making; patient-provider communication; diabetes; African-Americans.
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INTRODUCTION

Shared decision-making (SDM) has been defined as a process where both patients and physicians share information, express treatment preferences and agree on a treatment plan[1]. SDM has been promoted in a wide variety of settings, including primary care[2–3], and is associated with important primary care outcomes such as improved control of diabetes and hypertension, and enhanced preventive care utilization[4–5].

Although SDM is understudied in African-Americans, disparities exist in several related concepts, suggesting that there may be less SDM in this population. For example, African-Americans experience less physician responsiveness and listening than White patients and describe their physicians as less participatory during clinic visits[6–7]. Communication disparities may be an important contributor to racial health disparities[8], particularly concerning chronic diseases (e.g., diabetes) where effective communication is important to optimal disease management. Addressing such disparities will involve understanding the barriers and facilitators to SDM among African-Americans. To date, however, there has been little research in this area[9–11].

METHODS

The methods have been described in detail elsewhere[11]. This study utilized a qualitative research design, specifically, a phenomenological research method, that consisted of individual semi-structured interviews (n=24) and five focus groups (n=27). Each focus group consisted of five to six people and lasted approximately 90 min; individual interviews lasted approximately 60 min. Enrollment continued until theme saturation was met[12]. Themes were similar in focus groups and individual interviews.

Eligible patients included African-Americans with diabetes who were ≥21 years old and had an established attending

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primary care physician (PCP) at an urban academic medical center. Participants were identified by searching administrative databases for diabetes ICD-9-CM codes and patient visit information. Three attempts were made to contact participants. Participants received a $15 grocery store gift card as an incentive.

Topic guides were created using constructs of the Charles SDM model[1,13], the theory of planned behavior (TPB)[14] and the ecological model (EM)[15]. These guides consisted of a list of open-ended questions and follow-up probes, and were pilot-tested and modified.

Interviews and focus groups were audio-taped, transcribed verbatim and imported into Atlas.ti 4.2 software. A codebook was developed using an iterative process[16]. Five coders created uniform coding guidelines, and, subsequently, each transcript was independently coded by two randomly assigned reviewers. Outstanding issues were resolved by the group. Concepts and themes were discussed by the research team, and a conceptual framework was created based on predominant themes that emerged from the data.

RESULTS

Patient Characteristics (Table 1)

The majority of participants were female (82%), and half were 40–65 years old. Sixty percent of study participants had completed at least “some college,” and approximately half had private insurance. The average duration of diabetes was 14 years.

Themes (Table 2)

Patient/Physician Power Imbalance. A dominant theme in this study was the perceived imbalance of power between patients and physicians, which participants described as being exacerbated by race. Some participants described feeling disempowered where they did not have “the right” to be involved in health-care decisions. Participants often reported that African-American patients may be more likely to defer to a physician’s authority, refrain from asking clarifying questions and avoid challenging treatment recommendations (vs. White patients).

Participants reported that physicians may reinforce these power dynamics by limiting the health information given to African-American patients, not engaging such patients in discussions about treatment options and being “overbearing” in their communication (vs. White patients).

Patient-related Barriers/Facilitators

Health Literacy. Health literacy includes access to health information and the ability to process such information in a meaningful way. Some participants felt unprepared to make informed decisions about their health because of inadequate medical knowledge. Others reported being unable to comprehend medical jargon and feeling too disempowered to ask clarifying questions. Conversely, when participants felt informed about their diabetes, they reported having more self-efficacy in talking with their physician, asking questions and participating in decision-making.

Table 1. Patient Demographics

	% (n=51)
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
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	43
1	29
2	22
3+	6
Co-morbid conditions	
Stroke	8
Coronary artery disease	19
Hypertension	70
Hyperlipidemia	47
Peripheral vascular disease	20

**Retinopathy, neuropathy, nephropathy or diabetic ulcers*

Trust. Participants noted that patient trust in their physician affects the patient/provider relationship, communication and decision-making patterns. Within the trusting relationships, participants reported feeling comfortable speaking up and asking questions.

Fear and Denial. Participants described fear and denial about having diabetes (and potential complications) as a potentially important barrier that keeps African-American patients from

Table 2. Shared Decision-Making Barriers and Facilitators among African-Americans with Diabetes and Illustrative Quotes

Patient/physician power imbalance	*"I thought that since I had these top doctors, that I probably had no right to question them on anything because they were the top of the line."*
	"I think it's harder for African-Americans because African-Americans don't like to communicate with authority. That's what kills us."
	"A lot of [African-Americans] are scared to speak up and ask questions and voice their opinions. Living in poverty, you're not used to getting certain treatment anyway…"
	[Moderator]: "So you really didn't feel comfortable with telling them if you had reservations [about treatment recommendations]?"
	[Participant]: "Right, that's what I'm saying…They probably would have said, 'Well who in the hell do you think you are?'"
Patient factors: Health literacy	*"I let the doctor manage my diabetes. Yeah, I leave it to him because he is the professional and he would know more about it than I would…"*
	"What you don't know, you don't know. If you don't know what you are supposed to be involved in, then you don't know… Maybe I'm not even supposed to be taking what I'm taking. How do I know? I'm going by what my doctor says."
	"I think now that I have become a little more knowledgeable about the disease, I don't hesitate to question, to ask, 'What's the benefit of this pill?'"
	"You just have to be your own person—strong enough to question the treatment that you get. Go buy you a medicine book that's number 1, buy that book. If they give you some medicine and you don't want to question, then go home and look it up. That way you'll have the guts enough to call the doctor and say, 'Hey, I don't think this is right for me' or whatever."
Patient factors: Trust	*"[My doctor] took time and I felt like I could trust her…now I feel more comfortable talking to her about my health. She would listen and talk to me about decisions and medications."*
	"Maybe blacks don't ask their doctors [about] the different things that they want to know. Maybe they don't trust their doctors…"
Patient factors: Family experiences	*"At first I was thinking, 'Do I really have diabetes?' And I was thinking about the family members that had it—I had a great grandmother who actually went blind and had amputations—and it really hadn't dawned on me that it could go that direction. But still, that probably made me think about how you are really playing with fire. So now I talk with Dr. X about it, and now I'm on track with it."*
Patient factors: Fear/denial	*"…I just think black people are just afraid. I think black people are afraid and don't want to tell their doctor what's wrong with them. So some people are just afraid."*
	"I think I was probably 'chicken' and didn't want to hear [about my disease]…I think I could have talked to them if I had wanted to…"
	"A lot of [African-Americans] might not want to know the truth…"
Patient factors: Self-efficacy	*"Well, at first I really didn't understand about the diabetes, but I felt better when I got the meter…That's when I really felt good, and I tell everybody now that 'If you don't have a meter to test yourself, you just don't know'… The meter has really helped, and when my husband uses his, then I use mine."*
	"You know I have become a little…I don't know what you call it. Well, I'm no longer a 'scaredy cat', you know. You get kind of tough or bold… I'm a little bolder [when talking to my doctor] than when I started."
Physician factors: Information-sharing and patient education	*"Well, I feel that some [physicians] you 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."*
	"[Doctors] are just people like you. You know, talk to them just like you are talking to a friend. So if you can't understand him, you talk to him where he can understand you. And then you have to bring him to your level, or sometimes the doctor might have to bring [you] up to his level…"
	"Sometimes doctors speak in a whole different language. Have them draw it out. Make figures and pictures that you can understand. And tell them to explain THAT."
Physician factors: Validation of health concerns	*"[Doctors] need to listen to what you're saying and understand what you are saying…how are they supposed to know what's bothering you if they don't listen?"*
	"Well, I was trying to tell them about them about my health and they weren't listening. My sugar was low and I said to them, 'Didn't I tell you that I would fall out?'"
Physician factors: Physician medical knowledge/rechnical skills	*"They know more about the treatments and what's pertaining to the treatments, and if they suggest it to me and explain it to me, then I will make the other half of the decision regarding whether I should take it or not. And I like that about them bringing it to me."*
	"They took a real deep interest in finding out what's wrong, so that's why I felt like I could talk to them about anything. Because they were real inquisitive and well-trained."
Physician factors: Accessibility and availability	*"She took time to see and hear what I would like to say about my health. She would listen and talk to me about decisions and medications…she took the time to listen…about half an hour."*
	"Just all around she is good—a good person, a good doctor…When I am ill and I call her for advice or something, she returns my call."
Physician factors: Interpersonal skills	*"Some [of the] things that made me comfortable with him is that he just had a personal touch… He made you feel good and…he really tried to—he had a warm personality, you know."*
	"I think it's easier [to talk to my doctor about my treatment preferences] because I have been with her for the last 3 years and I tend to like her more and more as time goes on."
	"[My doctor] told me that he likes for me to ask him questions, because he said that when you're a patient and you're educated, it's much easier to treat you…So if I'm affected [with a problem], I'm supposed to let him know…He's a very good doctor and he's very receptive…he's a very nice person and I like the way he does things…"

fully engaging in discussions with their physicians about their disease and its management.

Family Experiences. Participants reported that prior exposure to diabetes through the experiences of family members may facilitate SDM because of the increased diabetes knowledge obtained, the additional motivation to avoid diabetes complications witnessed first-hand and the presence of additional social support to help during clinical visits.

Self-efficacy. Self-efficacy was described as an important facilitator (if present) and barrier (if absent). When participants felt more knowledgeable about their disease, and more capable of self-management, they had increased self-efficacy to talk to their physician about their health issues and participate in SDM.

Physician-related Barriers/Facilitators

Information-sharing and Patient Education. Study participants stressed the importance of having physicians fully disclose and explain test results, address knowledge gaps and discuss medical problems in "layman's terms." They believed that African-Americans were less likely to experience such information-sharing than Whites, although some patients identified strategies that encourage physicians to provide more clinical information.

Validation of Health Concerns. Participants noted that having health concerns "heard" and validated by their physician was important to maintaining open communication and in creating a sense of partnership that facilitates SDM. Participants believed that African-Americans are less likely than Whites to have their health concerns validated.

Medical Knowledge/Technical Skills. Several study participants said that a physician's medical knowledge and technical skills would enhance their ability to participate in SDM. They reported that confidence in their doctor's skills would increase their comfort in discussing treatment options, because decisions would be based on accurate medical information.

Accessibility and Availability. Participants appreciated when their physician was easily accessible (e.g., via phone) and devoted adequate time and attention to them (in and outside of the clinic setting). They noted that such accessibility afforded more opportunities for relationship-building and more time to communicate effectively with their physicians.

Interpersonal Skills. One of the most powerful SDM barriers/facilitators in our study was a physician's interpersonal skills, which were described as facilitators at a ratio of 2:1 over a physician's medical knowledge and technical skills. Interpersonal skills were described as essential to establishing a meaningful patient/provider relationship and creating an environment where patients feel comfortable expressing their concerns, being honest about adherence and playing a more active role in health-care decisions. Interpersonal skills and relationship-building were felt to be particularly important to African-Americans, who disproportionately mistrust health-care providers[17].

DISCUSSION

We found that African-Americans with diabetes reported a range of patient- and physician-related barriers/facilitators to shared decision-making with their physicians. These barriers/facilitators have the potential to modify the patient/provider power imbalance, which was perceived to be exacerbated by issues of race. Physicians can work to reduce this power imbalance and promote SDM among this population through several mechanisms. Perhaps most importantly, physicians can utilize and enhance their interpersonal skills to create an "emotionally safe" space in which patients feel supported and empowered to engage in SDM. When patients receive verbal and non-verbal cues that their opinions are valued, they are more likely to respond with active participation in health-care decisions[18].

In addition, physicians can address specific barriers (e.g., patient education, health literacy and sociocultural issues) within the clinical setting. For example, ensuring that low-literacy health materials are given (not just made available) to patients with diabetes, communicating with patients in "layman's terms," directing patients to community resources, using "teach-back" and other evidence-based approaches to patient education[19], and proactively enrolling patients in diabetes education classes can help address the health literacy barriers that disproportionately affect African-American diabetes patients. Beginning conversations about familial experiences with diabetes and engaging family members during appointments may enhance SDM as well as diabetes outcomes, as there is evidence that familial support of communication behaviors can enhance diabetes self-efficacy[20]. Asking patients about potential fears or concerns that arise from having diabetes and sending affirming messages to patients about their diabetes management (to enhance self-efficacy) are additional potential ways for physicians to begin addressing the sociocultural issues that may affect SDM among this population. Because primary care physicians often have long-standing patient relationships, they may have the requisite rapport (and opportunity for ongoing discussions) to begin addressing the barriers/facilitators to SDM identified in our study.

This study has several limitations. The study took place in a single academic medical center and consequently our findings may not be generalizable to all African-Americans with diabetes. Also, this research utilized a purposeful sample of patients. Patients who had particularly strong and/or negative communication experiences with their physicians may have been more likely to join the study.

Nonetheless, our study has several strengths. It focuses on a specific illness and sociocultural context, and allows a deeper understanding of SDM barriers/facilitators within a specific patient population. Also, this study utilized a multi-method approach that allowed analysis of different data types and enhanced our ability to arrive at valid conclusions.

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Conflict of Interest: *None disclosed.*

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REFERENCES

1. **Charles C, Gafni A, Whelan T.** Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Soc Sci Med. 1999;49:651–61.
2. **Larson EB, Fihn SD, Kirk LM, et al.** 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.
3. **Richardson WC, Berwick DM, Bisgard JD, et al.** Crossing the Quality Chasm: A New Health System for the 21st Century. Washington: Institute of Medicine; 2001.
4. **Stewart M, Brown JB, Donner A, et al.** The impact of patient-centered care on outcomes. J Fam Pract. 2000;49:796–804.
5. **Greenfield S, Kaplan SH, Ware JE, 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;3:448–57.
6. **Cooper-Patrick L, Gallo JJ, Gonzales JJ, et al.** Race, gender, and partnership in the patient-physician relationship. JAMA. 1999;282:583–9.
7. **Johnson RL, Roter D, Powe NR, Cooper LA.** Patient race/ethnicity and quality of physician communication during medical visits. Am J Public Health. 2004;94:2084–90.
8. U.S. Commission on Civil Rights. Available at: http://www.usccr.gov/. Accessed on June 4, 2009.
9. **Richter DL, Kenzig MJ, Greaney ML, McKeown RE, Saunders RP, Corwin SJ.** Physician-patient interaction and hysterectomy decision making: the ENDOW study. Ethnicity, needs, and decisions of women. Am J Health Behav. 2002;26(6):431–41.
10. **Sanchez MA, Bowen DJ, Hart A Jr, Spigner C.** Factors influencing prostate cancer screening decisions among African American men. Ethn Dis. 2007;17(2):374–80.
11. **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):450–58.
12. **Glaser BG, Strauss AL.** The discovery of grounded theory. Chicago: Aldine; 1967.
13. **Charles C, Gafini 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;44:681–92.
14. **Ajzen I.** The theory of planned behavior. Org Behav Human Decis Process. 1991;50:179–211.
15. **McLeroy KR, Bibeau D, Steckler A, Glanz K.** An ecological perspective on health promotion programs. Health Educ Q. 1988;15:351–77.
16. **Morgan DL.** Focus groups as qualitative research. 2nd ed. Thousand Oaks, CA: Sage; 1997.
17. **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):642–47.
18. **Ong LML, de Haes JCJM, Hoos AM, Lammes FB.** Doctor-patient communication: A review of the literature. Soc Sci and Med. 1995;40 (7):903–8.
19. **Paasche-Orlow MK, Parker RM, Gazmararian JA, Nielsen-Bohlman LT, Rudd RR.** The prevalence of limited health literacy. J Gen Intern Med. 2005;20:175–84.
20. **Coffman MJ.** Effects of tangible social support and depression on diabetes self-efficacy. J Gerontological Nursing. 2008;34(4):32–9.