Disparities in Shared Decision-Making Research and Practice: The Case for Black American Patients

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VISUAL ABSTRACT

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OBJECTIVE The extent of shared decision making (SDM) use in the care of Black patients is limited. We explored preferences, needs, and challenges of Black patients to enhance SDM offerings.

METHODS We performed interviews with 32 Black patients receiving type 2 diabetes care in safety-net primary care practices caring predominantly for Black people.

RESULTS The following 4 themes emerged: preference for humanistic communication, need to account for the role of family in decision making, need for medical information sharing, and mistrust of clinicians.

CONCLUSION Given the dearth of research on SDM among ethnic and racial minorities, this study offers patient-perspective recommendations to improve SDM offerings for Black patients in primary care settings. To enhance SDM with Black patients, acknowledgment of the importance of storytelling as a strategy, to place medical information in a context that makes it meaningful and memorable, is recommended. Triadic SDM, in which family members are centrally involved in decision making, is preferred over classical dyadic SDM. There is a need to reconsider the universalism assumption underlying contemporary SDM models and the relevancy of current SDM practices that were developed mostly without the feedback of participants of ethnic, racial, and cultural minorities.

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INTRODUCTION

Type 2 diabetes (T2D) is especially prevalent among racial and ethnic minorities.[1-3] Black and Hispanic Americans are at increased risk of T2D compared with non-Hispanic White Americans,[4] and similar disparities exist in other countries.[4,5-7] Black persons with T2D often experience barriers related to health disparities and social determinants of health such as the environmental conditions in which they live, low socioeconomic status, and low health literacy. These factors add unique and additional burdens to the daily effort of ongoing T2D management,[8] which interfere with the quality of T2D treatment compared with White individuals and are associated with high rates of T2D disengagement, treatment nonadherence, and worse health outcomes.[9-12]

Shared decision making (SDM) is a recommended practice to improve health communication and decision making and is particularly recommended for patients with T2D, for whom it has been evaluated in research and clinically offered to patients for >2 decades.[13-15] Shared decision making is particularly important when caring for medically underserved minority patients because it acknowledges the various preferences, values, and barriers related to engagement in diabetes care activities and can improve diabetes outcomes.[16]

Despite the promising results of SDM when applied to T2D care,[13] its implementation and use with Black and other ethnic and racial minority patients is limited, with few studies focused on SDM and ethnic and racial minorities with T2D.[17,18] The limited scope of SDM studied in T2D with Black patients found that patient-clinician power imbalances were exacerbated by race and served as a barrier to initiating SDM.[19,20] These findings stand in contrast to dominant SDM models that assume universalism in patient-clinician communication; that each medical discussion has the same communication principles regardless of diagnosis, patient,

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or setting.[21,22] Whereas such medical SDM models have become the norm for SDM research and practice, they have not advanced the implementation and use of SDM with ethnic and racial minorities and with Black patients in particular. This is because studies involving Black individuals and SDM are scant, particularly in T2D, unlike the rich volume and scope of research on SDM and T2D with White and Western participants from high-income countries.[16,23-26]

To understand what prevents SDM from being broadly implemented and used with Black patients, we investigated the preferences, needs, and challenges around SDM as experienced by Black individuals with T2D, and offer possible adaptations and modifications for SDM models, practice, and research with Black communities.

METHODS

Setting and Context

During the period August 2019 to February 2020, we recruited participants from the primary care practices at a safety-net hospital serving medically underserved racial and ethnic communities, most of whom are Black patients with T2D (80%, an average of 3,000 patients a month). The clinics are located in Philadelphia, Pennsylvania, one of the largest cities in the United States and ranked fourth for diabetes prevalence.[27-29] More than 70% of the patients served by the clinics are of low socioeconomic status and participate in federal health assistance programs. Eligible patients for the study were Black individuals with T2D defined by *International Classification of Diseases*, 10th Revision, Clinical Modification Diagnosis Code E11.x, aged ≥18 years, English speakers, and who had an established relationship with an attending primary care physician (≥1 appointment in the past year). This study was approved by the Temple University Institutional Review Board (protocol #25352).

Recruitment Procedures

We conducted an initial screening of potential participants for eligibility criteria and contacted them via mail and telephone. Patients who agreed to participate were invited for an in-person interview. Informed consent and Health Insurance Portability and Accountability Act authorizations were obtained, and participants were offered $35 in cash after completing the interview.

Data Collection Procedures

We developed an interview guide based on recommended domains of SDM,[30,31] on literature that addresses the communication needs of patients from racial and ethnic minority groups,[17,19,32] on previous experience developing interview guides for SDM studies,[25,33-35] and on personal experiences of the research team members. The guide focused on participants' familiarity with SDM and their attitudes toward and feelings and thoughts about SDM in general and in the context of T2D care. We also asked about unmet needs, challenges, and facilitators related to SDM practice in their care and about issues related to race, culture, racism, and disparities (eg, cultural/gender discordance).

At the end of the interview, participants completed the 9-item Shared Decision Making Questionnaire (SDM-Q-9),[36] a self-reported measure of perceived experience of SDM. When completing the SDM-Q-9, they were asked to think of their most recent clinical T2D appointment. The items describe different clinician behaviors, such as sharing treatment options and asking the patient about their preferences, that represent the SDM process. The questionnaire has been translated into 25 languages and has good psychometric qualities.[37] The Cronbach α in the original study was 0.938,[36] with similar results found for different samples, in different countries, and in different languages.[38] For each of the 9 items, participants responded using a 6-point Likert scale ranging from "completely disagree" (1) to "completely agree" (6). Summing all items yields a raw total score of 0 to 45. Multiplication of the raw score by 20/9 provides a score transformed to range from 0 to 100, where 0 indicates the lowest possible level and 100 indicates the highest extent of SDM.

Participants provided demographic information, and we reviewed their medical records for diagnosis and/or comorbidities, prescribed medications, and glucose level. A trained research assistant (J.S.) conducted recruitment procedures and the in-person, semistructured interviews in a private room in the clinics. Interviews were recorded and lasted 30 to 45 minutes.

Data Analysis

We coded interview transcripts using Dedoose, a web-platform application for analyzing qualitative research. We used IBM SPSS Statistics software version 24.0 for statistical analyses. We conducted qualitative data analysis using thematic content analysis,[39] which resulted in a rich description of the data set. The first author (Y.Z.-I.) developed a coding manual iteratively to guide the thematic coding, ensure ongoing reliability, and lead the qualitative analysis meetings. Analysis was conducted independently by 2 trained research assistants (J.S., J.L.) along with the first author (Y.Z.-I.). We later organized themes as central themes and subthemes.[40] We discussed disagreements regarding assigned codes during weekly team meetings, which were resolved by consensus.

RESULTS

Sample and Patient Characteristics

After a sufficient level of saturation based on the study's aim was achieved,[41] the total sample included 32 Black patients, men and women, with a T2D diagnosis. One-half of the participants (n = 17; 53%) were women, and the sample mean age was 59 ± 11.9 years (Table 1). Patients exhibited a range of glycemic control (mean [SD] glycated hemoglobin [HbA_{1c}] = 8.96% [2.7%]; range, 6%-14%).

Qualitative Analysis

Four themes emerged, as follows: preference for humanistic communication, a need to account for the central role of family members in decision making, a need for medical information, and mistrust of clinicians as a barrier to initiating the SDM process. Each is discussed, along with subthemes that suggest encouraged clinician behaviors (see Table 2 for pertinent quotations).

Preference for Humanistic Communication

Show empathy and build rapport. The most common theme reflects participants' preferences for humanistic communication. Participants wanted their physicians to express empathy, concern, and compassion as part of the medical appointment. Many participants wanted to be able to share their personal story with the physician, even if not related to T2D, and wanted the physician to show a general interest in them as persons above and beyond their diabetes symptoms. Specifically, doctor-patient encounters in which the doctor asked about the patient's family matters and listened to stories, daily experiences, or other health conditions and concerns were remembered as helping in diabetes management and were preferred by participants.

Use ice-breaker gestures. Almost all participants mentioned that ice-breaker gestures, such as the use of a first name for the doctor and patient, hugs, and humor, are needed to humanize the interaction and support successful clinician-patient communication and SDM. A 61-year-old woman said, "She [the doctor] come in with a handshake [to greet me]. [It's] very important because I feel as though I could have confidence. It gives you confidence."

Facilitate level-playing-field interaction. Participants reported preferring that their doctor talk with them and not at them, on a "level playing field." For example, a 52-year-old man said, "I don't like when some doctors bark at you, like, 'You need to do this and that'…and so we [the doctor and I need to] have discussions."

Table 1. Demographic and Clinical Characteristics (N = 32)

Variable	Mean (SD)	No. (%)
Age, y	59 (11.9)	
18-39		3 (9)
40-65		20 (63)
>65		9 (28)
Female		17 (53)
Black Americans		32 (100)
Marital status		
Single		10 (31)
Married		13 (41)
Separated/divorced/widowed		9 (28)
Education, y		
9-11		7 (22)
12		14 (44)
>13		11 (34)
Employment status		
Full-time		6 (19)
Part-time		3 (9)
Irregular work/unemployed /other		23 (72)
Primary diagnosis		
Type 2 diabetes		32 (100)
Total participants with comorbidities		26 (81)
Treatment regimen (n = 26)		
Diet		1 (4)
Oral drugs and/or diet		11 (42)
Insulin		4 (15)
Oral drugs and/or insulin		7 (27)
Insulin and/or GLP1RA		3 (12)
HbA_{1c} (%)	8.96 (2.7)	

GLP1RA = glucagon-like peptide-1 receptor agonist; HbA_{1c} = hemoglobin A_{1c}.

Need to Account for the Central Role of Family Members in Decision Making

Often, family members are involved in the management of T2D and join the T2D appointments. A 65-year-old man pointed out the importance of including his wife, "Well, my wife is very supportive [in my diabetes care] because she's the one that has to cook and make sure I'm eating right." Participants also talked about the importance of incorporating family members as part of T2D decision making to facilitate adherence and engagement with the prescribed treatment.

Need For More Medical Information

Participants reported feeling that they do not know enough about their T2D and cannot think of a way to ask their doctor about it. Some reported seeking this information themselves or reluctantly accepting the situation. A 69-year-old woman said, "As a matter of fact, I didn't know what it [HbA_{1c}] was and [at first] didn't care." Other participants expressed dissatisfaction with the information provided about their prescribed treatment and felt that they did not understand why it was prescribed or what it does, but that there was nothing they could do.

Mistrust of Clinicians

Clinician mistrust was commonly reported. This seemed to occur when the physician was on autopilot or the patient felt unseen or not really "known" to the clinician or staff. Half of the participants reported experiencing negative communication. A 66-year-old man described, "[The doctor] was just telling me stuff that I already knew, what to do, what not to do, and what to eat. And I've been a diabetic I guess for 15 years."

Decrease autopilot communication. Robotic communication, or on autopilot, led to miscommunication, enhancing mistrust, and making patients develop antagonism even before the beginning of the appointment. The quotation in

Table 2. Themes and Subthemes Suggesting Encouraged Clinician Behaviors and Pertinent Quotes

Preference for humanistic communication	
Show empathy and build rapport	[I like that] the doctor was a person that was a human being. She cared. She listens to you. She just don't zoom in like you're in a factory on the assembly line. She takes time out and listens to her patients. And she enthused me. (59-year-old woman)
Use ice-breaker gestures	He [the doctor] laughed at my jokes. I mean, it weren't like they weren't funny, but he laughed at my jokes. I had him cracking up. And that was when I was in a lot of pain. (52-year-old man)
Facilitate level-playing-field interaction	My doctor never talking against me. He's always talking *with* me. It's always what *you* really need to consider, what *you* really need to do, what *you* need to really make happen right away. (66-year-old man)
Need to account for the central role of family members in decision making	
	He [the doctor] takes his time with us to talk because me and my mama come together [to the appointment] and he talks to both of us. She had diabetes too. So however long it takes he'll take his time with us. (59-year-old woman)
Need for more medical information	
	My doctor decided to give me medication. I had been on the borderline for like 2 years. And so I can't remember exactly why he decided to prescribe medication, which I don't fully understand. I don't feel that I need it, but he's a doctor, so I go along with it. But I still have in the back of my mind, why do I need medication?? Because usually, I take my sugar glucose. I'm supposed to do it twice a day, but I only do it once. But it's never beyond 120. Usually the range it runs like 114, 104, below like 120. I never have a glucose reading of 150 or 200. I think it's [supposed to be excessive in the] 200 range, 150 range or something. But I never had that, so I don't fully understand. I'm being treated because my doctor recommended with medication. That's when I got metformin. But I don't fully understand it, but that's what he prescribes. So he's a doctor. (77-year-old woman)
Mistrust of clinicians	
Decrease autopilot communication	He'll [the doctor] come in and say "Good morning," "How is my day," all these type of things, "What are you here for today?" and I look like, Why did he ask me that? Ain't he supposed to know?? [...] I think that doctors don't have to converse with you like, "How's your kids or mom? Did you see the game yesterday?" or something like that, but at least acknowledge that your patient isn't patient number 42. (61-year-old woman)
Be direct and open	His [the doctor's] approach is perfect, in my opinion. Somebody else, it may not fit. But he just straight with me, I'm straight with him. Anything he ask, I blurt out. (52-year-old man)

Table 2 reflects the patient's frustration. Whereas the clinician seems to have tried to initiate small talk with the patient in an effort to break the ice, a step often recommended in the SDM literature, the patient perceived the clinician's intention negatively, which then affected their engagement in care. As the 61-year-old woman said, "If you leave your doctor's office and you feel like he wasn't paying attention, you're going to be wary to come back the next appointment." Finally, patients preferred direct and open communication. A 52-year-old man explained, "I want he just straight with me."

Quantitative Analysis

The quantitative self-report results of the SDM-Q-9 showed high levels of SDM (mean [SD] score, 5.03 [0.57]; sum score, 80.5 [11.5]) (Table 3). However, a deeper look at the distribution of the 9 items comprising the scale showed lower means for items 3 ("My doctor tells me there are different options for treating my medical condition"), 6 ("My doctor asks me which treatment option I prefer"), and 7 ("My doctor and I thoroughly weigh the different treatment options"), which address the sharing component of the SDM process in the scale.

DISCUSSION

Results of the present study offer insights and patient-perspective recommendations for SDM in T2D care with medically underserved Black patients. On the basis of the views and perceptions of and the preferences for SDM among participants in our sample, humanistic communication should be a basic

Table 3. Distribution of SDM-Q-9 Items (N = 32, range 1-6)

	Mean (SD)
Mean score	5.03 (0.57)
Sum score	80.5 (11.5)
Individual items	
1. My doctor makes clear that a decision needs to be made.	5.0 (0.92)
2. My doctor wants to know exactly how I want to be involved in making the decision.	5.0 (0.6)
3. My doctor tells me there are different options for treating my medical condition.	4.91 (0.96)
4. My doctor precisely explains the advantages and disadvantages of the treatment options.	5.05 (0.67)
5. My doctor helps me understand all the information.	5.25 (0.51)
6. My doctor asks me which treatment option I prefer.	4.72 (0.51)
7. My doctor and I thoroughly weigh the different treatment options.	4.72 (1.28)
8. My doctor and I select a treatment option together.	5.13 (0.83)
9. My doctor and I reach an agreement on how to proceed.	5.16 (0.77)

SDM-Q-9 = 9-item Shared Decision Making Questionnaire.[36]

strategy for SDM.[42] In the participants' views, humanistic communication includes honest expression of empathy and rapport building; use of ice-breaker gestures such as humor, smiles, and handshakes; and a level-playing-field dynamic, in which the doctor talks with the patient, rather than at the patient. Making room for storytelling,[43-45] a strategy that places medical information in a context that renders it meaningful and memorable, can overcome some of the cultural barriers to addressing emotional issues with Black Americans. Our findings also point to the need to prioritize a triadic SDM approach,[46] whereby family members take substantial part in the decision making, over the classic dyadic SDM that involves just 2 participants, a patient and a clinician. Because the family often plays a central role in T2D management for Black individuals,[47,48] more consideration and attention should be given to expanding SDM to a 3-way discussion.

Our findings also highlight which clinician behaviors to avoid. Impersonalized care and an autopilot communication mode are highly discouraged because they increase the patient's mistrust of the clinician. Direct and open communication is preferred, perhaps even the blunt sharing of the difficulty experienced by the clinician to break the ice over any artificial robotic attempt to communicate. Finally, perhaps one of the most disturbing findings is related to lack of information sharing about T2D and care options. Information exchange is a basic principle in any SDM model and guidelines.[30,31] However, information is not always shared with patients who are members of racial/ethnic minorities, and they often feel discouraged from asking questions.[24,49,50] This leads to an unintentional disparity in offering and using SDM.[26] Our quantitative results, measured by the SDM-Q-9, provide additional support. Whereas the overall score showed a good level of self-reported SDM, a detailed observation of the distributions of the 9 items showed lower levels for items addressing information sharing (item 3), elicitation of preferences (item 6), and deliberation (item 7).

Practice Implications

As identified in our sample of Black Americans with T2D, our findings have higher-order implications for the need to address disparities in engagement methods, particularly in SDM research and clinical offerings for chronic conditions.[24,26] According to the Purposeful SDM approach,[51,52] common SDM tools assume universalism in patient-clinician communication; that each medical discussion uses the same communication principles regardless of diagnosis, patient, or setting. A recent systematic review of SDM tools found that common tools for T2D (ie, decision aids) focus on discussing medical options (risks and benefits) but neglect contextual factors, such as social determinants of health, race, ethnicity, culture, socioeconomic status, and racism, in health care.[53] This situation is not unique to T2D; it is also observed in the context of other health conditions.[54] This is a serious drawback of existing SDM tools,[55] especially for Black Americans, who often experience high levels of the above-mentioned barriers.[20,32,56,57] For example, Black patients with T2D reported that their need to share information and to be heard by their clinician exceeds mere symptom reporting and medical advice,[18] which might explain the limited offering, use, and effectiveness of SDM and other communication tools among this group. In the field of mental health, for example, this weakness of SDM limits its dissemination, and some SDM interventions in mental health include additional factors, other than medical or clinical, that affect medical discussions.[54,58-60] Therefore, there is an urgent need to expand SDM offerings and use for Black, Indigenous, and people of color (BIPOC), who could benefit the most from culturally sensitive SDM.

The present study has several strengths. First, we conducted it in primary care clinics that predominantly serve BIPOC. These clinics are part of a safety-net hospital that serves one of the most marginalized populations, which are often medically underrepresented in research, particularly in SDM research. Second, our team is diverse, and BIPOC and other minority members were involved throughout the study including during data collection, interpretation, analysis, and writing. Third, we used a formative qualitative approach that allowed us to gain in-depth insights into the perspectives, preferences, and views of the study participants.

Nonetheless, study limitations include the fact that participants were residents of Philadelphia; hence, our findings might not be generalizable to Black individuals with T2D living in rural areas and/or other US cities or to other ethnoracial groups. We did not document the number or length of appointments with primary care clinicians, which could affect SDM because a major barrier to good SDM is short appointment times.[61] In addition, whereas we did not collect data on the gender, race, and ethnicity of the clinicians for each of the 32 participants, there were slightly more women than men clinicians in the participating clinics, and clinicians were overwhelmingly (>85%) White.

To summarize, addressing unconscious/conscious biases and differences in care delivery that lead to inequitable health outcomes is critical for the ability to move forward toward better health care for all. Our findings offer meaningful and needed insights into, and recommendations for, future use and adaptations to make SDM more valuable in the care of Black patients and other ethnoracial minorities. Future studies should focus on enhancing and adjusting current SDM tools and practices for marginalized communities that experience ineffective communication with their clinicians and worse health outcomes, and on developing new strategies for culturally sensitive and meaningful SDM. Taking into account clinician demographics, future research directions should also focus on the interaction of clinician-patient ethnicity and race on SDM and communication outcomes.

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Key words: shared decision making; health disparities; Black/African Americans; type 2 diabetes

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