

SOCIOCULTURAL INFLUENCES ON AFRICAN AMERICANS' REPRESENTATIONS OF TYPE 2 DIABETES: A QUALITATIVE STUDY

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Objective: Illness representations, known as patients' beliefs and expectations about an illness, may be influenced by cultural beliefs and personal experiences. This study explored African Americans' perceptions of the sociocultural factors that influence their representations of diabetes.

Design: Six semi-structured focus groups.

Setting: Private space at a convenient site.

Participants: Forty African Americans, aged 45-60 years with type 2 diabetes for at least one year prior.

Results: Participants perceived that there was a race-mediated effect of how they developed diabetes because of poverty due to past slavery, racial discrimination by health care providers, and the stigma associated with diabetes within the African American community. Participants perceived that poverty influenced African Americans' unhealthy eating habits, which led to diabetes diagnosis among their ancestors and their development of the disease since it was hereditary. Participants also perceived that there was provider ill intention, ie, providers were purposefully making people sick, and their lack of education on diabetes from providers was done on purpose, as information on diabetes was withheld and not shared due to racial discrimination. Perceived stigma by the community led to African Americans' avoidance and denial of the disease, and subsequently the development of diabetes.

Conclusions: To enhance disease management for African Americans with diabetes, it is important to focus on the sociocultural context of how African Americans view their world that may be influenced by their knowledge of negative historical circumstances and their current provider relationship, which, in

INTRODUCTION

The incidence of type 2 diabetes and related complications is disproportionately higher among African Americans (AAs) in the United States.^{1,2} AAs with diabetes have twice the rate of blindness and a three-fold higher rate of diabetic neuropathy, end stage renal disease, and non-traumatic lower extremity amputations compared with non-Hispanic Whites.³ In recent years, a recognition of diabetes as one of the most challenging chronic illnesses to manage led to a dramatic increase in research focused on psychosocial issues related to diabetes.⁴ This focus is important especially for AAs who are likely to face multiple psychosocial challenges while living with the disease and are likely to have varying perceptions of diabetes that might shape their health behavior.⁵ Based on limited quantita-

tive data regarding racial/ethnic minorities with type 2 diabetes, culture, socioeconomic status and psychosocial factors (including social support, self-efficacy) play a significant role in explaining diabetes self-care behaviors and outcomes.^{6,7} Qualitative research provides some additional information on the many psychosocial factors influencing self-care management among AAs with diabetes.^{8,9} However, in order to design culturally tailored treatment adherence interventions for AAs with diabetes, it is important to also explore how sociocultural factors might influence disease self-management and medication adherence via illness representations, especially given the social context in which adherence behaviors occur.¹⁰

Various reasons, including AAs' cultural beliefs, have been suggested for the disproportionate burden of diabetes among AAs and AAs' low

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interest in performing self-management behaviors.¹¹ AAs with diabetes are likely to have negative beliefs and attitudes about diabetes and perceive worse control of their illness.¹²⁻¹⁴ Optimal diabetes self-management behaviors can be hindered by cultural views such as personal hopelessness and fear of discussing diabetes complications with health care providers,¹⁵ cultural traditions,¹⁶ ineffective provider-patient interactions, need for psychosocial support, and religious practices.⁸ These potential cultural influences on

The objective of our study was to explore the sociocultural factors influencing the illness representations of AAs with type 2 diabetes.

diabetes self-management may also hinder medication use among AAs with diabetes. For example, a belief in the use of home remedies vs prescription medications may lead to nonadherence to prescribed medications.

Our study explores how AA patients' beliefs might be influenced by contextual cultural influences using a theoretical framework, known as the Leventhal's Common Sense Model.¹⁷ Illness representations, defined as "patients' beliefs and expectations about an illness" are central in this model, which also proposes that perception of the cause, timeline, controllability, symptoms, and consequences of an

illness are formed by patients and influence their coping behaviors.¹⁸ For patients with diabetes, these schemas (illness representations) drive coping behaviors, decision-making, and action plans by predicting their self-management behaviors (ie, medication adherence, blood glucose monitoring, and glycemic control).¹⁹⁻²¹

Patient illness representations are formed based on knowledge obtained from the sociocultural environment (eg, family, friends, media), influential sources such as health care providers, and individual personal illness experience (eg, symptoms or anxiety associated with the disease).²² Illness representations of AAs with diabetes might be constructed by their experiences with family members dealing with diabetes, their personal experiences, sociocultural and/or sociopolitical background, and knowledge about health care providers. While AAs with diabetes may respond to their illness experience based on their beliefs about diabetes and their conscious and implicit knowledge of what the disease means, sociocultural issues from their environment could also influence their view of diabetes.

According to the Common Sense Model, patient illness representations are shaped by the cultural context of an individual.²³ For example, although a diagnosis of type 2 diabetes may pose a threat to the emotional and physical wellbeing of AAs, AAs could employ cultural protective characteristics to enhance coping and attain control of the disease. Attitudes and beliefs about self-protective and self-enhancing motivations for AAs who live within the sociocultural context of a legacy of racism may shape behavioral responses

to an illness and these sociocultural factors may also shape illness representations.²⁴ For example, AAs with diabetes may have self-motivated tendencies to detect the occurrence of, and protect themselves from racism, which might influence how they respond to being diagnosed with an illness and subsequently lead to a distrust of their provider's treatment recommendations. In addition, if AAs with diabetes are oriented to sustaining, defending, and enhancing their self-worth, they might believe in only self-control of diabetes vs the use of medications.²⁴

Consideration of the patient's view of an illness is important but understanding the context of their experience is paramount to their disease experience.⁹ Few studies have explored illness representations of AAs with diabetes. Limited literature recommends the incorporation of these beliefs in the design of treatment adherence interventions. However, an important issue to consider is that for health care providers to truly understand the context of disease management among AAs and tailor their adherence interventions, they may need to pay attention to the role that patient sociocultural factors play in the influence and adaptation of illness representations. To this end, the objective of our study was to explore the sociocultural factors influencing the illness representations of AAs with type 2 diabetes.

METHODS

Study Design

We used a qualitative approach with focus groups as the primary mode of data collection to explore the socio-

cultural factors influencing illness representations of AA adults with type 2 diabetes. An exploratory approach to examine the study objectives allowed us to engage AAs by understanding their experience with diabetes.

Study Participants

Using purposive sampling, we recruited AA men and women with type 2 diabetes aged 45-60 years taking oral diabetes medications. To be included in the study, participants had to self-identify as English-speaking and AA/Black. In addition, participants had to self-report a diagnosis of type 2 diabetes by their health provider at least one year prior, and be prescribed to take at least one oral diabetes medication. We included only individuals prescribed an oral diabetes medication because of the complexity of diabetes among individuals taking insulin. In addition, patients taking only insulin were excluded because of the possible complexity of their disease.

Recruitment

Participant recruitment occurred in various community sites within two different cities in a US midwestern state. The community locations included a federally qualified community health center, a church, senior centers, and apartment buildings. To recruit study participants, we collaborated with key informants within the community sites, AA community advisory boards, and community networks, and disseminated recruitment messaging through flyers and word-of-mouth.

Measures

A brief 3-minute questionnaire assessed patient sociodemographics

(including age, sex, highest level of education,) and clinical characteristics (self-reported health status). Upon obtaining written consent, participants discussed their illness representations regarding diabetes, and talked about their perception of how various factors within their sociocultural environment influenced how they developed and controlled type 2 diabetes. The focus group guide comprised open-ended questions related to the study objective (Table 1).

Data Collection

In a private room, six semi-structured, 90-minute focus groups were conducted in the two different cities. Each of the six focus groups were audio-recorded and moderated by the principal investigator (a PhD-level AA/Black individual with 6-7 years of experience conducting focus groups) and a trained AA research assistant who observed and wrote notes. The moderator described the study at the beginning of the focus group, appropriately redirected participants' discussion to the main topic if there were divergences, engaged quiet participants, and prevented stronger participants from controlling the verbalization of other participants in the group. A \$50 incentive was given to thank participants for their contributions at the end of each focus group.

Data Analysis

A certified transcriptionist transcribed all audio-recorded focus groups verbatim and a research assistant verified each recording against the written transcript to ensure accuracy. There were six overall transcripts. Qualitative content analysis was conducted to ex-

Table 1. Focus group questions

What made you think you would or would NOT get diabetes?
Where do people in your community get information about diabetes? How else do people learn about diabetes?
Some people's religion or faith influence how they think they got diabetes. What do you think?
In your opinion, how does the money you have influence why people get diabetes?
In your opinion, does a person's race influence how people get diabetes?
In your opinion, does racism in society influence how people get diabetes?
People sometimes say that their emotions affect how they think about diabetes. Does anyone feel that way?
How do people learn what to expect as they age with diabetes? What leads to those expectations?

plore the data. A qualitative data software, NVivo 10 (QSR International-Melbourne) was used to facilitate data coding, rapid retrieval and comparison of codes, allowing for categorization and organization of themes. Using open coding (which involves reading the transcripts repeatedly, developing a coding frame for the emerging categories and conceptualizing it into themes),²⁵ allowed the identification of items elicited during the discussion. The principal investigator and another research team member who is also skilled in qualitative research independently coded the transcripts and analyzed the data by identifying salient emerging themes using participant phrasing, repetitions and descriptions of meaningful events. The themes were compared across participants and focus groups to understand similarities, differences, and interrelations across the codes and themes. The analysis continued until data saturation "the point in which the researcher cannot discover new dimensions in the data set" occurred.²⁶

Subsequently, each team member involved in the analysis met to address similarities and discrepancies in coding and to resolve differences by consensus. All codes and themes were agreed upon before the interpretation of the results. After all analysis was completed, member-checking, a process used to explore the credibility of qualitative data,²⁷ was conducted by offering the results section of the paper to four focus group participants to check for accuracy and resonance with their experiences. After review, participants reported their experiences were captured and agreed with the results. No changes or additions were recommended.

RESULTS

Forty AA men and women participated in the study. Most of the participants were female (61.4%) with a mean age of 53.3 (± 4.9) years. The highest level of education completed for most participants was high school (n=11, 28.2%) or some college education (n=13, 33.3%). Many participants self-reported that they had fair health (n=17, 43.6%).

Two major themes emerged based on patients' perceptions of the sociocultural influences on illness representations. Themes included the roles of: 1) race, racism and poverty; and 2) the community.

Race, Racism and Poverty

Race and Poverty

Participants reported that poverty led to their diabetes diagnosis and limited their ability to control their diabetes. In addition, participants perceived

that they had diabetes because of a race-mediated effect related to past slavery and poverty. These factors influenced AAs' unhealthy eating habits, which led to diabetes diagnosis among their ancestors and their subsequent development of the disease since it was hereditary as shown in the quotes below.

0023: And I think that (race-related poverty and slavery) has something to do with it too, because...a lot of food that wasn't good for our system for the most part, because we ate the leftovers... So I think that probably has some influence on our bodies... that caused the diseases. ...I think what you put in your body certainly has a lot to do with it...our ancestors did what they did to survive, so they ate what was left or what was available, which maybe was not good for them...

0013: I said that it (diabetes) is higher in Blacks because of what we used to eat, because our ancestors, what they ate...to live. From Africa, the slavery and all that. We made with whatever we could to survive.

Race, Racism and Providers

There was deep-seated mistrust of health care providers among our study participants. The perception of privilege, influenced by race, might have driven the construction of the negative perception of health care providers and the distrust regarding them. For example, participants believed that there were competing incentives for providers to help with control of diabetes. Participants perceived that there was provider ill intention, ie, providers were purposefully making people sick. In addition, they perceived that providers withheld information on purpose

and the racial discrimination they experienced both contributed to their lack of education on diabetes.

0041: Well, I think it was about a money thing...why do you got to take this from when you're young? Why you got to take this medicine when you a certain age? Why all of a sudden...or later on in life you got to take this and all your life you ain't never took this type of stuff? See, ...it could be a big money scheme. It's financial...

Sub-themes

More specifically, several participants expressed common perceptions related to four sub-themes of the race, racism and providers category as demonstrated by the participant quotes below.

MISTRUST OF PROVIDER BECAUSE OF PATIENT'S RACE AND PROVIDER PRIVILEGE

0011: Because they (Whites) have never had to suffer. They have never had to work, and they've always had choice, which is called White privilege...the reason why the Black people cannot go to the doctor as easy as the White people is because of White privilege. It has existed in this country, and it will stay in this country until this country is no more.

0013: But, see, back then when you Black, they was afraid to go to doctors. In the south, they still don't trust doctors...They don't go to the doctors....

PROVIDER INCOMPETENCE AND UNFAMILIARITY WITH AAs' PHYSIOLOGY AND BODY TYPE

0015: Because they keep telling us one thing...they did not discover, misdiagnosed me for years, and it got

worsened to a point, and they don't know much about especially Black women and our body type. They said I had fibromyalgia. And I said, okay, I'm hurting all over and stuff like that. But really, it's the diabetes taking over here, nerve damage. So the misdiagnosis of our race...

M-002: I couldn't walk. I said, something wrong. I have to go to the doc...and then they got me in the hospital...These people could not get it right...they were giving me my shots. And one minute, I'm good. About two, three hours later, I'm back up there.

PROVIDERS FINANCIALLY BENEFIT FROM PATIENTS TAKING MEDICINES AND BEING HARMED AND SICK

0025: When I go to my doctors, primary, endocrinologist, pain management, physical therapy . . . they started kicking me with prescriptions. Every time I go, I get a new prescription. I'm on 10 different medications a day now. Sometimes, a couple of them are multiple times a day. I think that the pharmaceutical company and the doctors is in some kind of kickback together. Something is going on here.

0038: The general major, the cat that's in charge of giving the government the okay...to take these medicines saying that they're safe. We need to be up in his office. We need to take a trip to the pharmacy place...to the manufacturer where they make these pills, and then we can ask questions to them. Hey, what's happening with this?

0036: ...but the thing is the doctors don't want to because if they cure us of these things, they going to lose their money...I've been told that. ... They pay the doctors not to cure us.

PROVIDERS DO NOT SHARE DETAILED INFORMATION ABOUT DIABETES, WHICH IS RACIALLY AND SOCIOECONOMICALLY MOTIVATED

004: Yeah (a person's race influence how people get diabetes), just like we were saying that, well, when you're borderline, you know, they just watch it. And I'm sure that if it was somebody else, they would show them the diet that they need to be on and the walking, ...I'm just thinking that that's how it goes for disadvantaged and anybody else.

003: They need to say the whole story, because you only getting half of the story when you get diagnosed. You know, if you don't attack it like you're supposed to, then the consequences, I always say I wish I would have listened to them, because this disease is troublesome. I'm always got to take my pills. I always got to do this before I eat. I can't have this, I can't have that. I didn't know that before.

001: (Racism) I think it influenced our lack of education about diabetes. So, we don't have the same tools that we could use as preventative measures as non-Black people would have.

Stigma from Community Members

Participants reported that diabetes was stigmatized among family members and the AA community. The perceived stigma led to participants' avoidance and denial of the disease, and subsequently the development of diabetes. It is not clear why the stigma may have occurred. Participants reported diabetes as a "silent disease" that was prevalent in the community and talking about it was private and not shared in conversations.

004: ...some people want to be close-mouthed. They don't want to let people know that it's (diabetes) here. It's nothing like you can put a Band-Aid on... It's a process of what you have, to learn how to control.

0023: That's a tough one, I think, because I think that stigma is just a tough one. I think that's right up there with domestic violence. ...Of sharing that information or telling somebody that ... you have the disease (diabetes)... people kind of sometimes think, you know, it's nobody's business but mine when there's a lot of help out there.

0014: People are so silent . . . about diabetes. You'd never know they got it, you know. I know church members in the church, geez, I didn't know half of them had diabetes up in there, you know, when the lady asked the question, and they went to raising their hands... I guess I'm the same way. They probably don't know I got diabetes, you know. It's like a silent disease. You never know who got it.

DISCUSSION

In our study, participants' beliefs about diabetes were influenced by sociocultural factors such as race, racism, poverty and the community. Based on the Common Sense Model, for AA patients with diabetes, illness representation, which is shaped by their cultural context, is influenced by the broader sociohistorical and environmental contexts that patients associate with their life experiences.^{4,23} In our study, AAs perceived there was a race-mediated effect on the development and control of diabetes, which were rooted in the

effects of slavery and related poverty, perceived racial and social class issues, discrimination by health care providers and the representation/beliefs of diabetes in the AA community.

Our study findings showed that participants perceived that past historical events influenced their ancestors' unhealthy eating habits, which then led to familial diabetes and heritability of diabetes. Similarly, Wagner et al²⁸ found that AA women with diabetes perceived the historical legacy of slavery and segregation as playing a role in the onset and perceived cause of diabetes. Based on our study findings, there is a perception among AAs with diabetes that slavery and its associated poverty led their AA ancestors to eat "leftovers," which caused diabetes to develop within the family and it "inherently" was passed down to them.^{28,29} AAs with diabetes may also perceive that they are unable to control their disease and perform self-management behaviors including adherence because of the influence of poverty.

Our study results showed mistrust of health care providers among AAs with diabetes. It is possible the perception of provider privilege, together with the race of the patient, influenced the construction of the negative perception of health care providers and the distrust regarding them. Since AAs were the primary subjects of the Tuskegee experiments, there is an increased awareness and concern of the possibility of health providers doing harm to them because of who they are compared with other racial/ethnic groups. Health care providers need to become aware and educated on how AAs mistrust of providers influences

AAs' perception of the cause and control of diabetes, and how addressing these sociocultural issues in treatment practices may lead to improved diabetes outcomes for this group.

In our current study, participants perceived that health care providers were incompetent and not familiar with AAs' body type. As described above, AAs are known to have low trust in providers' competence compared with other racial groups.^{29,30} In keeping with our study results, Lukoschek et al earlier (2003) also found

Our study findings showed that participants perceived that past historical events influenced their ancestors' unhealthy eating habits, which then led to familial diabetes and heritability of diabetes.

that AAs were skeptical of medications, as they believed their use was part of a conspiracy by physicians, hospitals, and pharmaceutical companies to exploit AAs and test these medicines experimentally.³¹ For their AA patients with these embedded perceptions, providers would have difficulty in engaging these patients in conversations to address inaccurate perceptions of the cause or control of diabetes. Interventions to address and/or educate on the cause of dia-

betes as a means of improving medication adherence and enhancing diabetes management would also likely not be effective for this patient group.

Participants in our study reported that provider racism and discrimination influenced how they developed diabetes and hindered their ability to control the disease. For AAs, knowledge of the sociopolitical history of AAs with the health care system and personal experiences of racism in modern day health care environments may lead to the mistrust of health care providers.³² Knowledge of the history of racism in the health care system and the patient's personal experience with racism could constitute a broad cultural memory of abuse and lead to a belief in conspiracy theories among AAs, including a perception of how they developed diabetes.^{33,34} Regardless, AAs with diabetes who internalize these perceptions are likely to experience negative emotions about diabetes and poor management of the illness. Interventions that provide behavioral and psychological support for dealing with negative reactions to diabetes could be helpful for AAs with diabetes.

The participants in our study named two factors that influenced the development of diabetes: the AA family unit and the AA community. Similar to a prior study, diabetes among our participants was not discussed in the family.³⁵ Participants reported that diabetes was stigmatized among family members and the community, which led to avoidance and denial of the disease, and subsequent development of the disease. It is possible that diabetes is another "silent killer" in the AA community because it is taboo to talk about it.

Clinical Implications

Provider distrust cannot be separated from patient perceptions of racial discrimination and may be at the root of some illness representations.³¹ Hence, the development of trust and concordance during patient-provider communication, as well as education on the causes of diabetes and culturally appropriate ways of controlling the disease delivered by providers, could address AAs' perception of racism, influence illness representations, and enhance adherence and diabetes control. Interventions that encourage truthful discourse about mistrust of the US government and health care system, as well as conspiracy theories in the context of historical and current racial discrimination, are needed to achieve success in diabetes management.³⁴ To gain the trust of AA communities, health organizations, government institutions, public health entities, and health provider groups need to openly acknowledge the origin of these beliefs, and collaboratively work with social groups and community organizations to address current discrimination within the health care system.³⁴

To enhance self-management for AAs with diabetes, clinicians and other health care providers may benefit from having culturally appropriate and sociocultural-sensitive talking points about improving diabetes self-care and medication-taking behaviors. In the design of these talking points and other interventions, attention to patient-perceived racism and historical trauma due to slavery are potential areas to address to improve health outcomes. Future studies should examine the clinical outcomes of medication

adherence interventions that incorporate the key sociocultural issues reflected from this study's findings.

Limitations

Individuals within racial and ethnic groups may be heterogeneous with regard to beliefs, perceptions, and values that predict behavior; hence, the influence of sociocultural factors on illness representations might vary among AAs. This study was conducted in a US midwestern state where there are fewer AAs compared with other geographic regions of the United States. Since this is a qualitative study, the sample is not representative of all AAs with type 2 diabetes. The study was conducted among middle-aged AAs with diabetes. Future studies should consider including AAs of other age groups. Participants had varying educational backgrounds. It is possible that AAs' illness representations of diabetes will differ based on this factor, as there might be increased knowledge about diabetes among individuals with higher educational levels compared with individuals with lower educational levels.

CONCLUSIONS

In our study, AAs' perceptions about type 2 diabetes appeared to be situated in historical racism, slavery and its poverty effects, and affected by current experiences as a racial minority, which may manifest in mistrust and unfamiliarity with health care providers. The perceived stigma of diabetes within the AA communities of our study group may hinder AAs' ability to take control of diabetes. To

enhance disease management for AAs with diabetes, it may be important to focus on the sociocultural context of how AAs may be influenced by their knowledge of historical circumstances and their current provider relationship, which may, in turn, reflect unto their perceptions of diabetes and self-management behaviors.

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CONFLICT OF INTEREST

No conflicts of interest to report.

AUTHOR CONTRIBUTIONS

Research concept and design: Shiyانبola, Ward, Brown; Acquisition of data: Shiyانبola; Data analysis and interpretation: Shiyانبola, Ward, Brown; Manuscript draft: Shiyانبola, Ward, Brown; Statistical expertise: Shiyانبola; Acquisition of funding: Shiyانبola; Administrative: Shiyانبola, Ward, Brown; Supervision: Shiyانبola, Ward, Brown

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