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Perceptions of the Healthcare System Among Black Men with Previously Undiagnosed Diabetes and Prediabetes

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Abstract

Objective: Given the significant disparities in diabetes burden and access to care, this study uses qualitative interviews with Black men with HbA1c levels consistent with previously undiagnosed diabetes or prediabetes to understand their perceptions of the healthcare system.

Research Design and Methods: We recruited Black men from Black-owned barbershops in Brooklyn, NY, who were screened using point-of-care HbA1c tests. Among those with HbA1c levels within prediabetes or diabetes thresholds, qualitative interviews were conducted to uncover prevalent themes related to their overall health status, health behaviors, utilization of healthcare services, and experiences with the healthcare system. We used a theoretical framework from the William and Mohammed Medical Mistrust Model to guide our qualitative analysis.

Results: 52 Black men without a prior history of diabetes and a HbA1c reading at or above 5.7% were interviewed. Many participants stated that their health was in good condition. Some participants expressed being surprised by their abnormal HbA1c reading because it was not previously mentioned by their healthcare provider. Furthermore, many of our participants shared recent examples of negative interactions with physicians when describing their experiences with the healthcare system. Finally, several participants cited a preference for incorporating non-pharmaceutical options in their diabetes management plan.

Conclusion: To help alleviate the disparity in diabetes burden among Black men, healthcare providers should take a more active role in recognizing and addressing their own implicit biases,

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AUTHOR CONTRIBUTIONS

D.C.L., M.R., and C.Q. researched data, contributed to discussion, and wrote, reviewed, and edited the manuscript. M.O. and Y.A. researched data and reviewed and edited the manuscript. S.P.W. contributed to the discussion and reviewed and edited the manuscript. E.M.N. and J.E.R. reviewed and edited the manuscript. All authors approved the final version of the manuscript. D.C.L. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

DECLARATION OF INTERESTS

There are no potential conflicts of interest to report.

engage in understanding the specific healthcare needs and expectations of each patient, and consider emphasizing non-medication approaches to improve glycemic control.

Keywords

Diabetes; preventive screening; medical mistrust; minority health

INTRODUCTION:

Of the estimated 34.2 million Americans with diabetes, 21.4% are undiagnosed [1; 2]. Studies have found that people with undiagnosed diabetes were younger, rated their health status favorably, and were diagnosed with fewer comorbidities compared to patients with diagnosed diabetes (3; 4). Individuals with undiagnosed diabetes are also more likely to delay treatment and are, therefore, at higher risk for subsequent diabetes-related complications [5; 6]. To address this, it has been recently recommended by the U.S. Preventive Services Task Force that screening for diabetes should now start at 35 years old, and patients with risk factors, especially minorities, should be screened even earlier [7].

Black patients are disproportionately affected by diabetes as they are twice as likely to develop Type 2 diabetes and three to four times more likely to develop complications and die from a diabetes-related illness compared to other racial and ethnic groups [8; 9]. Black males have the highest mortality rate among adults with diabetes compared with other demographic groups [10]. In addition to earlier onset, recent studies show that significantly fewer Black males with diabetes survive into their 70s compared to Latino and White men [11]. Along with lack of access to care, insurance status, and time constraints, one of the possible contributing factors to these disparities is medical mistrust, which may cause Black men to be less likely to engage with the healthcare system [12; 13]. The reasons for medical mistrust need to be better understood in the context of the daily lives of Black Americans today [14; 15].

To investigate the patient perspective on medical care, this study uses qualitative interviews with Black men who had a point-of-care hemoglobin A1c (HbA1c) level consistent with either previously undiagnosed diabetes or prediabetes with the goal of gaining insight into their perceptions and experiences with the healthcare system. In this way, we hope to provide a deeper understanding of the experiences of the healthcare system that may be common among Black men, which can help us better address the racial disparities in diabetes outcomes.

RESEARCH DESIGN AND METHODS:

Study Design

This qualitative research study was embedded in a community-based diabetes screening program. Black men were approached while waiting for a haircut at one of eight Black-owned barbershops in Brooklyn, New York. Black-owned barbershops were selected as the community-based setting for this study because they are popular sites where Black men of all socioeconomic strata gather regularly and comfortably discuss various topics such as

their personal lives, current events, and social issues [16]. Additionally, prior studies have demonstrated the effectiveness of using barbershops as an ideal place for community-based healthcare intervention targeting Black men [17]. The barbershops in this study were located in communities previously identified as hotspots of poor glycemic control based on citywide analyses of HbA1c registry data [18]. Point-of-care HbA1c tests were used to screen participants for poor glycemic control. From September 19, 2017, to January 23, 2019, 692 Black men were approached to be part of the study. Of the 692 who were approached, 402 declined to participate. The top reasons for declining were not being interested, and already aware of their health status. There were 290 Black men who agreed to be screened, of whom 26 had a HbA1c result of 6.5% or higher consistent with diabetes, and 82 had a HbA1c result between 5.7% and 6.4% consistent with prediabetes [19]. Of these 108 Black men with evidence of poor glycemic control and no prior history of diabetes, we interviewed 52 of them to understand their impressions of their overall health, health behaviors, utilization of healthcare services, and experiences with the healthcare system. We partnered with the barbershop owners to offer a free haircut valued up to \$40 as compensation to those that completed the study.

Study Participants

Eligible participants were English-speaking, self-identifying Black men without a prior diagnosis of diabetes and were 18 years or older. Individuals with blood disorders such as sickle cell disease or those who had recently experienced blood loss were excluded as these conditions may interfere with HbA1c testing. Each participant was asked to answer a short series of questions describing their age, race/ethnicity, country of origin, the highest level of education received, and reported height and weight to estimate each participant's body mass index. Then, we performed the point-of-care HbA1c testing using the commercially available A1CNow+ test (PTS Diagnostics), which has been shown to be strongly correlated to standard venous HbA1c blood tests with a correlation coefficient of 0.93 [20]. Participants with HbA1c results of 5.7% to 6.4% were categorized as having previously undiagnosed prediabetes, and participants with a HbA1c result $\geq 6.5\%$ were categorized as having previously undiagnosed diabetes [19].

Qualitative Interviews

For study participants with a HbA1c level consistent with previously undiagnosed diabetes or prediabetes, we invited them to participate in a short, structured, audio-recorded interview immediately after their test result. A group of academic researchers and physicians created the set of questions designed to assess their perceived health status, health behaviors, utilization of healthcare services, and their perceptions of and experiences with the healthcare system (Appendix Table). Each interview was then transcribed verbatim and was reviewed by two members of the study team.

Theoretical Model

The William and Mohammed Medical Mistrust Model was used to guide inductive and deductive coding and interpretation of the interviews [21]. According to the model, underlying reasons for medical mistrust are driven by social institutions (e.g., the healthcare system) and reinforced by disparities in social status [22]. William and Mohammed also

describe proximal pathways such as cultural transmission (e.g., stigma, prejudice), stress (e.g., racial discrimination, historical trauma), and knowledge (e.g., about health and health status). All of these influences ultimately influence behavioral, psychological, and physiologic responses by individuals and their resilience, which can affect their health outcomes. Therefore, qualitative coding focused on identifying themes that pertained to the knowledge of participants about diabetes and their health status, episodes that might produce stress from overt or subtle racism, or implicit prejudices among providers and patients that might affect patterns of healthcare utilization or result in poor glycemic control.

Analysis

We first performed descriptive analyses on the study participant demographics, including age, detailed racial identity (e.g., Black, African American, African, Caribbean, etc.), birthplace, height, weight, and education. BMI was calculated based on self-reported values for height and weight. For qualitative analyses, two research coordinators, one Afro-Caribbean woman and the other a Latina (M.R. and C.A.), independently read a set of five transcripts to form an initial set of codes. Weekly team meetings were held to discuss transcripts and finalize the code list. Differences in thematic coding were adjudicated by the senior investigator, an Asian-American man (D.L.). ATLAS.ti software was used to code the second set of five transcripts. Once the initial codes were refined, the rest of the transcripts were analyzed. After the transcripts were coded, we developed a list of reoccurring themes. Quotes were then selected by the research team that was felt to best represent the predominant themes identified in the analysis. Interviews were performed until thematic saturation was achieved.

This study was approved by the NYU School of Medicine Institutional Review Board. All study participants provided informed written consent.

RESULTS

Study Participants

We screened and interviewed 52 self-identifying Black men with previously undiagnosed diabetes and prediabetes at Black-owned barbershops in Brooklyn, NY. Among the 52 participants interviewed, the average age was 42 years, and their mean HbA1c reading was 6.1%, ranging from 5.7% to 7.3%. Additionally, the average BMI was 30.6 based on self-reported weight and height, with a range from 22.6 to 45.8. Most of our participants self-identified as Black/African American (67.3%), followed by Caribbean or West-Indian American (17.3%), and 7.7% as Afro-Latino. In addition, 15.4% of our participants reported to be born outside of the U.S. (Table 1).

Summary of Themes

We used the William and Mohammed Medical Mistrust Model to guide our inductive and deductive coding and interpretation of the interviews. We established codes that may be indicators of proximal pathways of mistrust. From the codes, reoccurring themes that we found were misconceptions of health status, expressed suboptimal personal and vicarious experiences with the healthcare system, and prescription of medical management.

Misconceptions of Health Status

Though all participants had a HbA1c reading within the prediabetic and diabetic range, 20 participants expressed beliefs that they were in good to excellent health. As one participant said: *“I feel like superman. My wife said that to me today ‘You think you’re superman. Nothing bothers you.’”* [HbA1c: 6.2%, Age: 56].

Some participants associated good health with either having a lack of diagnosed chronic conditions, the absence of prescribed medications, or the absence of noticeable symptoms. Some participants believed that since they were in good health, they did not need to seek healthcare services. As one participant said, *“Well I haven’t had, well you know, I didn’t think I had any health issues. I haven’t had any health complications so I never went to anyone”* [HbA1c: 6.0%, Age: 45].

Similarly, when some participants interacted with the healthcare system, their providers would also say something similar. The patients were told that they were healthy, and their tests were normal, despite having evidence on our tests of previously undetected poorly glycemic control in our community-based screening. When asked to describe his health, one man said *“...every time I go to my doctor, and he say, ‘Mr. [participant’s name], you’re fine, keep it up.’ So if I never fine, him wouldn’t tell me ‘keep it up,’ right?”* [HbA1c: 6.2%, Age: Not disclosed].

Experiences with Healthcare

In addition, 26 participants shared mixed feelings when expressing their general attitudes towards healthcare providers. A common attitude shared by participants was reflected by statements like, *“It depends on the doctor. Some doctors are good and some doctors are bad. Some doctors I don’t even know why they’re doctors”* [HbA1c: 6.3%, Age: 32].

6 participants expressed explicit negative attitudes towards doctors. Common explanations were based on recent negative personal experiences with doctors. One participant described his relationship with the healthcare system as, *“I’m one of the person who doc... a doctor didn’t do right by”* [HbA1c: 6.1%, Age: Not disclosed]. Another participant described a negative encounter with a primary care provider who *“just checked my blood pressure, that was it but she didn’t actually come into the examination room and say like ‘why are you here?’ She wasn’t my primary doctor neither, but still in all... she was like ‘come into my office.’ No you need to come in here [the exam room] and check me.”* [HbA1c: 6.5%, Age: 57].

Perceptions of Medical Management

Once our participants learned that they had HbA1c levels consistent with poor glycemic control, 38 participants expressed an eagerness to take concrete steps to improve their glycemic control. *“I have to monitor myself; I have to watch what I eat. Get another checkup... Gotta make some adjustments.”* [HbA1c: 6.6% Age: 31]. Some participants were motivated by the losses they experienced with members of their family or community. As one participant stated *“Not wanting to die. Seeing my friends and peers die man... You know one of my friends died in the hospital at the doctor’s office because he wasn’t going*

and when it really got too bad, he wound up too late... And these men are my age. We in our mid-50s.” [HbA1c: 6.0%, Age: 54].

6 participants expressed a preference for non-pharmaceutical methods for improving their glycemic control. Some of the prominent reasons participants brought up for not wanting medication were fear of side effects and needing additional medications to counterbalance those effects. One participant said *“If I have to have one medication or multiple medications, then they have side effects, then I have to take another medication, it defeats the purpose. Then I’m a lifetime patient instead of being healed. My first thing is before they... if a doctor asks... or offer me any medications is to try to find out what I could do naturally to offset what is the problem” [HbA1c: 5.9%, Age: 52].*

Medication hesitancy was associated with mistrust in the healthcare system. Frequently, participants believed that the system prioritizes profits over patients, with some participants expressing how concern about how doctors’ behaviors are incentivized. One participant recounted, *“...it’s not doctors itself it’s just the whole medical profession itself... But, I think doctors will feed you with things that’ll make that minor issue turn increase into something more to keep the medical field in some type of business or keep it going” [HbA1c: 7.1%, Age: 39].*

Another reason for the reluctance to take medications was fear of dependency. Along with personal experiences, participants mentioned the experiences shared by their social networks and community members. One participant explained what happened to his friend when, *“They put him on all types of medication that he didn’t really need, but now he’s dependent the medication. That’s what I’m really afraid right there, like let’s find other alternatives first before we go to the end all be all” [HbA1c: 5.7%, Age: 31].*

DISCUSSION

In this study, we identified some of the underlying reasons for medical mistrust among Black men with previously undiagnosed diabetes and prediabetes. Through qualitative interviews, conducted in Black-owned barbershops we found that several Black men expressed concerns about the priorities of healthcare providers, especially the aspects of healthcare that act more like a business rather than putting the needs of patients first. After being told that they had HbA1c levels consistent with diabetes and prediabetes, many participants were strongly motivated to improve their health which is consistent with prior studies among Black men [23].

Several participants in our study also expressed a preference for non-medication options. Numerous studies have shown the higher efficacy of behavioral interventions to improve glycemic control over pharmaceutical options [24–27]. The findings of our study demonstrate how important it is for providers to be more mindful of working together with Black patients on the available treatment options. Some patients may only want medications as a last resort, therefore, there should be a more robust emphasis on how to support patients in making sustainable lifestyle changes to improve their glycemic control [28].

Additionally, it was evident in our study that Black patients often have strained relationships with their healthcare providers. Even when they would seek care from their clinicians, their recent experiences of perceived mistreatment led many to believe that the healthcare system does not work in favor of patients, especially if they are Black. This finding is consistent with previous research that identified differences in provider linguistics and culture as key factors associated with healthcare underutilization among Black men [29]. In our study, participants gave recent personal accounts of mistreatment that influenced their perception of the healthcare system rather than citing historical racism. Our participants shared their experiences in which healthcare providers demonstrated a lack of empathy or otherwise did not treat patients with respect. For example, in the encounter presented earlier, we saw the patient whose healthcare provider asked him to come and be examined in an office rather than staying in the exam room. The patient believed that it was an instance of mistreatment and a lack of respect. From the provider's perspective, these instances might appear explainable and not a systematic effort to prevent Black patients from accessing care. However, implicit biases are pervasive and can be toxic to the patient-physician relationship [30; 31]. Given the broader societal context in which racism is widespread, any degree of mistreatment will impede the effectiveness of any therapeutic intervention and reinforce the belief that the healthcare system plays a role in perpetuating racial disparities [1; 32; 33].

Furthermore, we found that many of the Black men who had previously undiagnosed diabetes or prediabetes had a very positive impression of their health. We should not be surprised by this finding as poor glycemic control can be without symptoms until years later when diabetic complications have appeared [34–37]. Some participants were surprised to find out that they had undiagnosed diabetes or prediabetes as their doctors had previously said that everything was fine. This raises the concern of whether these Black men are not receiving appropriate preventive care, given that they are a high-risk group that should be screened much earlier for diabetes. Through inaction, some healthcare providers may directly contribute to health disparities and poor diabetes outcomes among Black Americans [38; 39]. Understandably, primary care clinics are already strained and poorly supported, however, our study highlights how physicians need to take an active role in reducing disparities by screening, diagnosing, and developing appropriate treatment plans for Black men who are at high risk of diabetes.

Our study had some methodological limitations. Given that the data used was originally from a broader qualitative study of Black men screened for diabetes, more specific questions about patient-physicians relationships may not have been asked. In addition, the sample obtained reflects Black men from specific neighborhoods in New York City that were identified as having a high prevalence of poor glycemic control. Our findings may not be generalizable to Black men living in other communities or parts of the country. Furthermore, although point-of-care HbA1c testing is used widely and has reasonable accuracy when compared with venous blood draws, our point-of-care HbA1c results should be followed by confirmatory testing.

In conclusion, our study explores medical mistrust amongst Black men with previously undiagnosed prediabetes and diabetes and identifies factors that may contribute to disparities in diabetes outcomes. Healthcare providers can help by eliminating any pessimism or bias

that they have in treating Black men, especially since we found that these patients are eager to improve their health upon being diagnosed with diabetes or prediabetes. As healthcare providers, we also need to engage patients, especially Black men, to understand their needs and expectations, be willing to adapt treatment plans, and consider non-pharmaceutical approaches, which are known to be more effective, as demonstrated by studies of the Diabetes Prevention Program [24; 25]. Finally, we need to ensure that we appropriately screen high-risk groups for diabetes and prediabetes, especially high-risk minorities. While Black men face many barriers to good health, we can be a positive force in reducing the long-standing disparities in diabetes and providing better care to those minority populations who need it the most.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1:

Patient Demographics

Characteristics	Cohort
Participants, No.	52
Age, Mean (Range)	42 (19 – 68)
BMI, Mean (Range)	30.6 (22.6 – 45.8)
% Obese (BMI >30)	21 (40.4%)
African	3 (5.8%)
Caribbean / West Indian	9 (17.3%)
Latin American	4 (7.7%)
Foreign Born	8 (15.4%)
HbA1c Mean (Range)	6.1% (5.7% – 7.3%)
% Diabetes	8 (15.4%)
% Prediabetes	44 (84.6%)

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