

BMJ Open Factors influencing health-seeking behaviours and self-care practices among black-African Caribbean people living with type 2 diabetes: a community-focused qualitative study from Southwestern England

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ABSTRACT

Background/objective To examine factors influencing health-seeking behaviours and self-care practices of diabetes, including the uptake and use of diabetic services among community-dwelling black African-Caribbean people living in the UK.

Design Cross-sectional/qualitative.

Setting Community (Southwestern England).

Participants Nineteen individuals of African-Caribbean heritage, over the age of 50 years, diagnosed with type 2 diabetes.

Methods Three focus group discussions (FGDs), each of which lasted for approximately 90 min, were held. These interviews were facilitated by a community-based health champion and a researcher of African-Caribbean heritage. Audio recordings were transcribed verbatim, coded in NVivo software, and analysed using an inductive thematic approach.

Primary outcome measures FGD data.

Results A total of nine culturally specific and non-specific (generic) themes were identified. Culturally specific themes included the normalisation of diabetes at the community level, which was more pronounced among men than women. Participants were found to be inclined to either substitute or complement diabetes medications with cultural herbal remedies. There was a lack of trust in medical centric advice received from healthcare practitioners. Participants also expressed that healthcare practitioners do not always listen to or understand their needs and reported that there was a lack of culturally appropriate diabetes education and training programmes for their community members. Generic themes included difficulties and frustrations in getting doctor's appointments, self-indiscipline and poor motivation for engaging in physical exercise and healthy eating.

Conclusion Several cultural/community-related factors influence health-seeking behaviours and self-care practices of diabetes in African-Caribbean people living in the UK, often affecting men and women differently, alongside more general individual and healthcare system-related barriers. Addressing these factors is imperative in designing a culturally and demographically tailored diabetes education programme for these people.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ African-Caribbean people with diabetes from grass-roots communities outside London, where people may have different demands and needs of health-care services and healthcare-seeking behaviours and lifestyles were examined.
- ⇒ A racially concordant community health champion, and a researcher of the same background, facilitated participant recruitment and data collection, allowing for the capture of rich data.
- ⇒ How the study findings may be used in designing a culturally sensitive diabetes education programme for African-Caribbean people is highlighted.
- ⇒ Data were collected from a specific region in south-western England, limiting transferability of findings.
- ⇒ Multiple methods of data collection such as one-to-one interviews and online surveys were not used to corroborate our findings, due to resource limitations.

INTRODUCTION

Diabetes mellitus, a metabolic disease characterised by high blood glucose levels, is a major public health problem, with more than 537 million adults estimated to be affected worldwide.¹ Black people from African and African-Caribbean ancestry, who account for approximately 3% of the UK population,² are up to three to five times more likely to be affected by diabetes than white Caucasians.^{3 4} It is estimated that by 2025, approximately 10% of black African-Caribbean and 5% of black African people in the UK will have diabetes.⁵ A comparative study conducted in newly diagnosed cases of type 2 diabetes across various ethnic groups living in South London found that blood glucose levels are significantly higher in black African or African-Caribbean people (possibly due to delayed diagnosis) compared with white

Europeans, consequently putting them at greater risk of early complications of diabetes.⁶

While medical intervention plays a critical role in reducing blood glucose levels, structured diabetes education programmes around the management of diet and medication, the importance of exercise and the importance of monitoring diabetes control through engagement with health services are equally essential in promoting patient awareness and improving self-care practices.⁷ The effectiveness of structured diabetes education programmes is widely recognised to be influenced by cultural beliefs and practices.⁸ However, the evidence guiding the development of culturally tailored diabetes education programmes for African and African-Caribbean populations living in the UK thus far has been sparse. Two studies are noteworthy. Goff *et al*⁹ noted several cultural beliefs and practices that healthcare professionals (HCPs) perceived to be barriers to diabetes self-management among African and African-Caribbean people living in two inner London boroughs (where there are greater concentrations of African and African Caribbean people). These barriers included distrust of conventional medicine, a preference for natural remedies, belief in 'food myths', faith in 'God's will' and cultural views that favour larger body sizes or associate weight loss with illness, which leads to stigma. Brown *et al*¹⁰ examined the perspectives of people living with diabetes, in the Midlands city of Nottingham, finding similar barriers to the management of diabetes in African-Caribbeans. Furthermore, Brown *et al* also found that control of diabetes in these communities is also influenced by their memories of growing up in the Caribbean, their migration history and perceptions of diabetes held by their friends and family. This suggests possible community-level/shared influences on the management of one's diabetes.

Goff *et al*¹¹ evaluated the acceptability and feasibility of a culturally tailored diabetic training programme for black people, which focused on healthy eating and an active lifestyle¹² (constituting 14 hours of group-based culturally tailored diet and lifestyle education, behaviour change support and supervised physical activity spread across 7 weeks). Participants were recruited from the London boroughs of Lambeth and Southwark and were randomly assigned to either the control arm (usual care) or the intervention arm. The intervention was found to be highly acceptable where 85% of participants attended the programme 6 weeks or over. To our knowledge, this is the *only* study from the UK to have designed a culturally appropriate diabetes education programme for black people (although a heterogeneous sample that included black British, African and African-Caribbean participants was used, and the clinical and cost-effectiveness of the programme was not examined), and none exists specifically for African-Caribbean people in whom diabetes is estimated to be more prevalent (10%) compared with black Africans (5%).⁵ It is noteworthy that participants in the Goff *et al*¹¹ and other abovementioned studies were highly selective, being mostly from London and/or from primary care databases or practitioner referrals who were invited to participate through

emails (prone to 'selection bias'), hence limiting the generalisability of findings, particularly at grassroots communities outside London, where people may have different demands and needs of healthcare services and healthcare-seeking behaviours and lifestyles.

London has quite a different ecosystem compared with the rest of the country, and each county has its own challenges. So, for example, people outside London may face varying levels of deprivation, limited access to specialist care services and longer travel times to reach those services.¹³ Furthermore, outside of London, the job market may be smaller and less diverse, with fewer opportunities for high-paying or specialised roles. Hence, talented and more educated individuals are often drawn to London from other cities in pursuit of better career prospects. Also, the demographic composition of cities outside London can differ distinctly from that of London even within a given ethnic group, which may impact people's health-seeking behaviours. Yet, its impact on African-Caribbean people in the UK has not been adequately explored, in particular, in different demographics.

African-Caribbean people in the UK face unique challenges, including disproportionate stop-and-search practices and over-representation in the criminal justice system compared with other minority groups.¹⁴ Black people were found to be five times more likely to be stopped and searched by police across Avon and Somerset bordering Bristol Channel,¹⁵ where the proportion of African Caribbeans is greater compared with other ethnic minority groups including South Asians. African-Caribbean people, particularly those less educated, view governmental officials and health workers often with suspicion,¹⁴ which could limit not only their health-seeking behaviours and uptake of health services but also their participation in health research. Involving a trusted community champion throughout the research process can be vital in improving their participation and promoting open and friendly discussions with rich data. While previous studies in the USA have demonstrated the effectiveness of such recruitment strategies,^{16 17} no comparable studies have been conducted within the African-Caribbean community in the UK.

The aim of the current study was to explore barriers to improving knowledge, awareness, attitudes and practices related to diabetes control, including gender-specific factors influencing the uptake of diabetic health services among community-dwelling black African-Caribbeans with type 2 diabetes in and around Bristol, a major British city outside London with a significant black population.¹⁸ To ensure trust and rapport in accessing participants and in the ways that we engaged with participants in the focus group discussion (FGD), a trusted community champion was involved.

It is anticipated that the findings from this study will provide valuable insights and contribute to the development of improved structured diabetes education and self-management intervention programmes tailored to the

cultural needs, beliefs, lifestyles and healthcare-seeking behaviours of African-Caribbean individuals living in grassroots communities across the UK.

METHODOLOGY

This qualitative descriptive study used focus groups to explore diabetes-related knowledge, beliefs and practices and community-level influences on diabetes management and engagement with health services, among black African-Caribbean people in a grassroots community. The reason FGDs were conducted was to gain a deeper understanding of collective community-level influences that might be unique to the setting. Individual factors affecting health-seeking behaviours were also explored. We have used a similar methodology in people with diabetes from other ethnic minority groups, including South Asians.¹⁹ In addition, we were also mindful of significant challenges related to recruitment, participation and engagement when carrying out research on ethnic minority groups. Peer support afforded in a group format often facilitates better participant engagement, especially as mistrust of researchers due to negative past experiences has been reported.²⁰ We, therefore, believe that a FGD addresses challenges by providing a trusted and safe community space to facilitate engagement as well as open and honest discussions.

As evidence suggests that participants are more likely to share their experiences when invited by trusted community champions or networks,^{16 17} a racially concordant community-based health champion facilitated participant recruitment within the community. The study is reported following the guidelines of 'Standards for Reporting Qualitative Research'.¹⁷ A preliminary version of this manuscript was deposited on the Research Square preprint server²¹ and was subsequently revised to its current form to provide insights into the implications of our findings for men's health and patient-centred consultations, and other relevant areas.

Patient and public involvement

Patients or the public were not directly involved in the design, conduct or reporting of the research findings.

Inclusion criteria

Individuals self-reporting a clinical diagnosis of diabetes from their doctor and belonging to African-Caribbean descent.

Exclusion criteria

Individuals below 18 years of age, individuals with dementia and learning difficulties, and individuals who were not able to provide informed written consent.

Participants

Out of 20 individuals who expressed interest in the study, 19 participants (6 men and 13 women, all over the age of 50 and self-reporting as having type 2 diabetes) (Table 1) attended and provided written informed

Table 1 Demographic composition across three FGDs

Focus group	Males	Females	Diabetes type	Age group
1	2	5	Type 2	>50 years
2	2	4	Type 2	>50 years
3	2	4	Type 2	>50 years

consent to take part. All participants were able to speak and understand English. The majority of the participants shared a common heritage and culture, predominantly of Jamaican ancestry. Participants were given a shopping voucher for their time.

Recruitment and data collection

Recruitment was conducted through existing networks using purposive and snowball approaches and through advertising on posters/flyers at the community centre. A total of three FGDs were conducted (two face-to-face, one virtually). Participant distribution across each FGD was as follows:

The FGDs took place in the locally accessible community centre. The virtual FGD was included to accommodate those participants who had concerns about COVID-19 infection. Each FGD lasted approximately 90 min. Thus, approximately 4.5 hours of focus group interview was obtained. The interviews were preceded by a brief overview of the research.

A paired 'insider' and 'outsider' approach was used to conduct FGD and data analysis.²² The discussions were facilitated by a researcher (PK-D) and a community health champion (CL), both of African-Caribbean heritage (insiders), while another qualitative researcher of non-African-Caribbean heritage (RS) attended as an outsider. This recognised that expressions of people's lived experiences often remain told within only one community.²³

Author PK-D, a qualitative health researcher, has extensive knowledge of community engagement and qualitative methodologies. She is also a practising nurse with experience in managing long-term health conditions, including diabetes. PKD holds a PhD in linguistics and an MA in sociolinguistics, focusing on discourse in diabetes consultations with black Caribbean communities and doctor-patient interaction. CL, a lay researcher and community health champion, was employed as a research assistant for this study and trained to facilitate FGDs. She has extensive experience in community engagement.

The FGDs were guided by predefined topics (see online supplemental file 1) relating to their understanding and beliefs about diabetes, access to diabetic health services and their skills and abilities to enact diabetes self-care practices. The topics were explored through a semistructured format, that is, having eight clusters of predefined, open-ended questions, which were carefully considered to address the research questions and to guide the open discussions, while also allowing for spontaneous and in-depth responses from the participants

and for themes that the researchers had not anticipated to emerge. Data were appraised, against the topic guide after each focus group session. To address issues of quality assurance, during our analysis, we identified recurring themes relating to the question categories and the spontaneous ideas expressed by participants. There was no new information emerging eventually after three focus groups. Therefore, the focus groups were considered sufficient,^{24 25} and the questions we were exploring were adequately answered. Our sample size is similar to a previous qualitative study by Brown *et al*¹⁰ that used 16 participants.

To minimise bias, the moderator topic guide was developed based on gaps identified from the literature, the aims and objectives of the study and our experience of working with diabetes people from minority ethnic groups.¹⁹ The questions were independently peer-reviewed by all researchers before reaching a consensus. CL played a key role in both recruitment and the development of the topic guide. Additionally, author RS took on the role as an objective moderator in the sessions to ensure that the study objectives were addressed. During the data analysis, all experienced researchers (RS, JR, SP) provided a critical perspective on the insights arising from the data interpretations. Final interpretations were validated by participants in a subsequent community workshop, that is, member-checked.^{10 26}

The spoken medium emerged spontaneously in the group settings and ranged between Jamaican Creole English and/or other Caribbean English (Patois) and English as spoken in the UK (both of which are intelligible to CL and PK-D). That is, some participants switched (and also mixed) between Patois and UK English. Communicative competence in this flexible use of language became important in the data coding, analysis and interpretation, where interpretation of the underlying meanings participants ascribed to phenomena was a cocreated process between participants and researchers.

The face-to-face focus groups were audio recorded using a digital voice recorder in MP3 format and the audio of the virtual focus group session was captured through the Microsoft Teams transcription.

The moderator topic guide was peer-reviewed independently by individual researchers before reaching a consensus. The guide was free of any leading questions. We thoroughly examined for overlapping data and provided contextual details about the data collection site (community centre), participant's demographic characteristics (age, gender, type of diabetes, ability to speak and understand English) and procedures of data collection. Such measures have been suggested to improve the trustworthiness of qualitative research findings.²⁷ Furthermore, a paired insider-outsider approach²³ ensured balanced data interpretation, while PK-D served as an 'insider' 'outsider' researchers (RS, JR, SP) were able to question the insights arising from the data interpretations. Final interpretations were cross-checked with participants and presented in a feedback workshop for validation.

Data coding and analysis

Data were coded using NVivo²⁸ and analysed thematically, using Braun and Clarke's six-step methodology.^{29 30} Coding and themes were cross-checked by multiple researchers to ensure consistency. Subthemes emerged as participants expressed their experiences and perceptions, often contrasting with predefined questions. Initially, audio files were transcribed verbatim using a university-approved service. A second round of transcription was completed by PKD, a linguistic discourse analyst, following true verbatim conventions. In instances where participants spoke Jamaican Creole (Patois), their quotes were translated into UK English for clarity and have been presented accordingly. Arbitrary pseudonyms have been given to the participants.

RESULTS

Themes and subthemes were identified under the following broad topics: (A) factors impacting self-management and uptake and engagement with diabetic services. (B) Factors impacting dietary self-management practices. (C) Perceived individual and community needs. An exhaustive list of quotes is provided in online supplemental file 2. The main findings are discussed with example quotes below:

Factors impacting self-management of diabetes and uptake and engagement with diabetic services

Theme 1. Health beliefs

Subtheme 1. Getting diabetes is perceived as normal and inevitable

There was a prevailing perception among participants that diabetes was highly common in their community. The perceived threat of serious health or lifestyle consequences of diabetes was indicated to be lowered by the 'normalisation and acceptance' of diabetes. Representing the participants' general perspective, Joseph described that people in the community tended to suppress thoughts of developing diabetes, while also viewing the disease as something 'inevitable'.

Joseph: 'I don't know any person [of] my age or just before me in my community who is not diabetic.... diabetes to some people is... just a norm... it really became a norm. ...when I was a young man growing up in Jamaica every old person had sugar... But nobody went to the doctor.'

Joseph: I sit in the local pub with the younger people between 40 and 50 years old. They do not care about diabetes. It is not even something they think about... They see me and say- boy you look good for your age, you look healthy. Although I might have diabetes, to them, I look healthier than some of them.

Joseph's comment also suggests that viewing older diabetic people as looking well and living normally without taking medication or not seeking medical help

can make some younger community members think that diabetes is not a serious disease.

Subtheme 2. Differing perceptions of 'healthy food'

Participants expressed scepticism about publicly available information on healthy diets for diabetes. Barry noted that some foods marketed as healthy often undergo processes like injection, which he believes compromise their healthfulness. In contrast, he considers traditionally grown Jamaican foods, without such manipulation, to be healthier. As a result, Barry finds it challenging to eat healthily and instead aims to make the best of his situation.

Barry: '...this eat properly thing is kind of technical to me because they grow the food in labs, the food all injected, we don't know what they inject them with to grow.'

Barry: '... if you were in Jamaica you'd plant your own food- you wouldn't fertilize it, so it would grow from the natural ground, everything from the ground, now they want [it] to come [very quickly] because they have something to [push the growth along]. It doesn't grow [naturally], they just push it ...we have to just try and make the best of the circumstances.'

Barry also expressed suspicion and mistrust of eating certain cultural foods like rice, believing they are often tampered with for profit, which he feels makes them unsafe to eat.

Barry: 'I have to directly avoid rice because rice is not [really] rice- when you cook rice sometimes it is very sweet- it is not [really] rice.'

This scepticism about the 'healthiness' or 'suitability' for consumption of certain foods was further reinforced by Joseph's account (below) of an incident when he first came to England. He described being advised not to eat a particular type of melon because, although categorised as healthy food, it was considered 'artificial' due to having white seeds instead of the familiar 'natural' black seeds, suggesting that food that is unfamiliar causes suspicion about whether it is grown healthily.

Joseph: '... the melons have white seeds and a man said to me 'you mustn't eat that one you know, the artificial one'. But the melon was pretty. But then [the man said] 'look at the seeds'- it didn't have black seeds like what we know, it has white seeds- you shouldn't eat that one because that's not the good one... they produce it differently [not grown organically].'

Furthermore, a predicament whereby people with diabetes can be enticed to choose less healthy food options, such as burgers, over 'healthy' Caribbean food (eg, ackee), due to such food being comparatively more affordable, was noted.

Joseph: 'You are sitting there and you're watching [tv] commercials and it says protect your diabetes, but

then the next advert is a Burger King advert. Where you can buy a tin of ackee for like six pounds for the small tin but you can buy four burgers for three pound. You in a predicament.'

Subtheme 3. Scepticism about prescribed medications

Scepticism and mistrust regarding diabetic medication were also prevalent among some participants. Joseph voiced a deep mistrust in medical guidance due to the inconsistent information he received from doctors. He feels confused and frustrated when prescribed medications that are later deemed unsafe, highlighting a broader concern about the reliability of medical advice and the impact of such changes on patient health and decision-making.

Joseph: 'I go to a doctor and the doctor says- you would get tramadol, and I say- how come you are giving people tramadol and it's making (people sick) and the doctor took up a book and switched [from what she had previously advised] and said- oh yes you should stop taking it. And I am thinking- I have been taking it all this time- ...So one min they tell you this is the answer, and then suddenly after [they change]. So that confusion is there.'

As such, doctors' advice and prescriptions were perceived to be 'experimental', leading to participants feeling discouraged, in some cases, in using prescribed medication.

Barry: '...it seems to me the doctor is just like me-he is just experimenting.'

Yvette: '... and they always want to put everybody on the same medication. I bet all of us on metformin. It must be a cultural thing, but it's like they want to start us on that [medication] to see what happens.'

Yvette's decision, below, to reduce her metformin intake due to its side effects suggests a lack of trust in her doctor's recommendations and reflects her preference for controlling her condition through extreme dietary measures, like starvation, rather than relying on medication.

Yvette: '... I was on that [metformin] twice a day, and I've cut it down myself to once...because it's [metformin] got quite a lot of side effects, it's kidneys and all that sort of thing and I'm trying not to take it and when I go to the doctor they didn't find anything wrong until the last time I went, and they said I have to take two. I still don't, I just starve myself.'

Theme 2. Preference for cultural herbal treatments

Participants showed a strong preference for the use of herbal treatments such as bitters, aloe vera, cinnamon and Moringa in managing their diabetes, often using them instead of or alongside prescribed medications. In some cases, herbal treatments were perceived to be so

effective that participants had completely discontinued or delayed the use of prescription medications.

James: 'I do not take any of those [prescribed medication]. I make sure the most time if I have anything sweet or eat, I have the bitters... I have my bitters to counteract it..... it's like I take more bitters and it [sweetness] just disappears.' '... I make sure I have some bitters. If I can't get one [bitters], I buy the aloe vera.'

Rosa: '... recently [from] my research, I found out that cinnamon... is very good for diabetes...they said there's a special ingredient or something in that particular cinnamon that is good for you.' '... well I certainly do think that since I've started taking the cinnamon as well that has helped. ...

Rosa: 'I've been diabetic for about seven years now, and every time I go, and they do their tests and everything, they do inform me that they would like me to go on – I can't even remember the name.... I keep saying I don't want any medication; I will keep with my diet and so far it's been so good.'

Andrew: 'I sometimes advise people to do away with the pharmaceuticals and go the herbal way. ...because I feel that the herbs would do a bit more than the pharmaceuticals. From experience, I've seen that it has worked, so why not? My mum has done it, it worked. A couple of people have done it, it all has worked, so for me I think the best bet would be straight onto the herbs.'

Joseph: 'I have medication [and] I do my moringa powder and all them.'

Barry's story (below) conveys a sense of hopelessness in that the doctors simply said his knee was not going to get better, which led him to try herbal alternatives. This may indicate that participants sometimes turn to the use of herbal treatments when other things do not seem to be working and/or when they have no alternative.

Barry: 'I had a bad knee and the doctor said 'it's not going to get better... you know the diabetes is [affecting] your knee'.... I just told [my friend in Jamaica] to tell a man to send some bush [herb] for me. That was two years ago, and now I have not had a bad knee again.'

Moreover, James highlighted his strong belief in the effectiveness of herbal treatments for overall health and his conviction that traditional herbal 'bitters' played a significant role in preventing diabetes and managing his condition.

James: '... I pluck up the courage and go to the doctor. ...and they said, "Right, you have to cut down the eating habit, you are two [number] away from type two [diabetes]", ... you must eat a lot of vegetables, [and] have exercise." ... 'I go out straightaway from there and buy one [bitters]... I take it for about two

weeks.... I go back [to the doctor] in two weeks and do a blood test, prick my finger, and he [the doctor] said, "I can't understand, a couple of weeks ago you were two away from type two. Now you're back to normal and beyond.'

The preference for herbal treatments seemed to be associated with cultural traditions that emphasise the use of herbal remedies, many of which are commonly found in tropical regions that are believed to effectively treat various health conditions (including diabetes) and maintain overall well-being. Below, Barry describes how he has not been reliant on doctors lifelong; rather, he treats illnesses (eg, a cold) by using herbal treatments (eg, tamarind bush).

Barry: 'I never went to a doctor, because if you have a cold, you just drink a lot of tamarind bush- boil it up and then you bathe in the tamarind water and in no time- that's gone... when I came to England and saw my mother with these whole heap of pills I said what [illness] do you have, she said diabetes- I said what is that- she said, 'well your blood sugar' and this and that... I was frightened when the doctor said I'm on the edge- I said, 'edge of what?' He said, "Diabetes- you're a diabetic person"- so I just said [to myself] you know what – I will go back home [to Jamaica] and look for my bush [herbal medicines] and grow them.'

A consistent finding among participants who confirmed their use of herbal treatments is that they would not disclose the use to their doctor. Instead, they would keep such information hidden. The reasons provided for this behaviour were that doctors would advise against it, fear of potential consequences and the perception that HCPs are not receptive to alternative management approaches.

Peggy: 'I don't tell them... [they would] tell you to stop.'

Barry: 'I was feeling terrified [of telling the doctor that I take bush].'

Theme 3. Effectiveness of health professionals and the healthcare system in meeting the needs of community members

Subtheme 1. The healthcare system does not meet patients' expectations

Some participants expressed a lack of confidence and trust in the judgement of healthcare practitioners. Others also shared their frustration about the 'effectiveness' of healthcare practitioners and the healthcare system with regard to meeting their expectations.

Brian: 'I trust certain doctors but the majority of them I don't trust their judgment... you go to a doctor and tell him you've got this, that. He just gives you a load of pills, "Oh, come back and see me three weeks later", and three weeks later you think, "What's the point in going? Nothing's happening". And that's the attitude of most black guys.' Delroy: 'Yeah, I go to the doctor, but they say the same thing over and over. "Lose weight". ... I've

been diabetic over 12 years now, more than 10 years, and I'm saying if these pills are supposed to be helping, why is it not going down?'

In the case of Delroy (below), the anticipation of doctors' effectiveness invariably stemmed from his prior experiences with physicians and the healthcare system in the Caribbean, whereby he perceived doctors in Jamaica to exhibit greater thoroughness, implying a heightened level of concern and dedication towards enhancing his health condition.

Delroy: '...In Jamaica, doctors test you [thoroughly]...[here]they do not give a toss if you're dead, gone tomorrow, you are just buried, do not move.'

These feelings are supported by participants' other concerns that doctors and the healthcare system do not listen to them or have no time for them. As a result, Joseph (below) suggests that he has to become his 'own doctor.'

Brian: '... The health service to me is there, but it is really doing nothing for me because at the end of the day they [Health care professionals]do not really have the time for me right now, so I have to try and become my own doctor.'

Subtheme 2. Difficulty getting appointments to access healthcare services

Participants reported experiencing significant frustration and barriers when trying to access healthcare services, highlighting issues such as long wait times, difficulty reaching healthcare providers and excessive questioning by receptionists, which may discourage patients from seeking timely medical assistance.

Andrew: 'Each time I phone [for an appointment] I've got to wait one hour and all I reach is the reception desk.'

Rosa: 'You ring up, and when you do get through, they [the receptionists] ask you 10 000 questions.'

Subtheme 3. Lack of trust and suspicion of authorities, including health professionals

Notably, among some male participants, a general lack of trust and suspicion of authority figures (eg, police) was evident. In the case of Delroy, below, this was extended to health professionals, and there was a suggestion that such a lack of trust might deter him from attending diabetes awareness sessions. Delroy also implies that the lack of trust stems from previous experiences, leading him to trust few people of his own kind (black).

Delroy: 'You know black people and you know black men- they do not want to do anything- they are just afraid and say I'm not going up there. I am not going to take part because I do not know where those people come from... trust is a big thing because a lot of people are hiding- the reason they're hiding is that

they claim- 'those people might have something to do with the government.'

Brian: 'I will never take part in [organized training event]...I do not know where the people [who give training] are coming from.'

Delroy: '[There are]four people that I trust, yeah?... they are all black.'... 'Walk a mile in my shoes and then you will say, I trust my own kind.'

When asked about the difference, a black professional would make with regard to engaging with education programmes, Delroy indicates that he is more likely to trust someone who understands his experiences as a black person. However, he also indicated that a status barrier may also influence engagement and a sense of feeling represented, as previous experiences with black health professionals whom he might regard as having higher status (from Cambridge University) have resulted in him feeling demeaned.

Interviewer: 'If you had black professionals that were talking to you, would it make a difference?'

Delroy: 'No, because basically, I've had black doctors try to talk to me [about diabetes], and all I can see is [they are from]Cambridge University, ... basically they talk to you as although you are beneath [their]feet.'

Within James' narrative, a suspicion of the motives of authorities and health professionals was evident. He explained that he withheld information from his doctor about how he managed to lower his blood sugar out of fear that sharing this knowledge could lead to its exploitation for commercial gain, preventing his community and future generations from benefiting.

James: 'He [doctor]said, "Somehow, I don't know what it is, but you seem to have the cure"...I think to myself, "No, I'm not telling him [how I cured]". ... 'the reason I never tell him was because I found out that we're all dying, especially in our community, and I scared if [he] knows what this is, [he would]take it off the shelf or test it, get that label off, put their own label, or they find the cure.'... I'm not thinking about myself, I'm thinking about us because we are the same generation, so I'm thinking, well, and I have children and grandchildren to think about...

Factors impacting dietary self-management practices

Theme 1. Adjusting the cultural diet to meet diabetic dietary advice

Overall, female participants were more aware of the need to reduce the carbohydrate content of their food, suggesting that depending too much on cultural meals may mean a high level of carbohydrate consumption.

Rosa: 'When it comes to the carbohydrates, I was just going to say that us from the Caribbean or from African descent, we have a lot of carbohydrates I think in our diet, if we eat our cultural food.'

Pauline: 'He [my husband] is eating all those heaps of meat, but I cook my vegetables for myself... sometimes I take a little piece [of meat].' Peaches: 'I have a breakfast bowl that I put my soup in, so it is less than the big black bowl I used to eat it in.'

Subtheme 2. Dietary advice is not culturally sensitive and clear

Participants were using varying strategies for dietary management. For example, Peaches focuses on strict dietary restrictions, while Pauline adopts a more flexible, moderation-based dietary approach.

Peaches: 'I just really stopped all the meat, all the chicken and fish... I eat loads of vegetables such as carrots, cabbage, I steam them [vegetables] together and have them alone, but not even with a little rice.'

Pauline: 'I eat everything but with moderation, the diabetic nurse told me that **sweet potato is good** for me and all those things but eat very small.'

Peaches: 'I now just buy the ordinary things and use in moderation, I do not take much, a bit of salt, a bit of everything.'

Delroy: 'Because you're of West Indian heritage, they're associating your diet with yam.'

Subtheme 2. Information about the Caribbean diet not represented in diabetes dietary advice

Participants also spoke about having to make imprecise estimations of traditional foods with the reference foods in dietary advice (eg, estimating how much yam is equivalent to a small potato, making smaller dumplings in the traditional soup (but might have quite a few), or use a smaller bowl for the traditional soup (so that they have a smaller portion)).

Helen: 'Well I think with the potatoes you can only have a small potato with your meal being a diabetic, so if you sort of measure that as a small piece of yam as well, or not a whole big slice of yam with vegetables.'

Suzette: '...I have a breakfast bowl that I put my soup in, so it's less than the big black bowl I used to eat it in.'

Rosa: '...I eat everything in moderation, because rather than have potato chips, I'll have sweet potato chips, and I'll have cassava chips as well, and I have a lot of fruits but also a lot of pulses, butterbeans, you name it, all the beans.'

Theme 2. Poor health literacy and poor understanding of diabetes advice

While most of the men had some awareness that reducing carbohydrate intake and engaging in exercise are recommended, there was an indication that on diagnosis and during subsequent interactions with HCPs, they might perceive a hierarchical relationship, such that they feel being instructed to *take these tablets* or *lose weight* without adequate explanation or understanding about managing their diabetes.

Delroy: 'When I go to the doctor, the doctor says, "You're borderline", and then the next couple of months he gives me tablets, say, "Take these tablets to cut down your diabetes because your diabetes is going up. I'm still eating the same rubbish, same stupid things. But he had seen my record and say, 'You know what, it's time for you to cut back on certain things because things is getting worse.'

Delroy: 'They don't go deep down and tell you, eating A, B, C, D can lead to diabetes', they only tell you, 'Cut off sugar'. Yeah, I go to the doctor, but they say same thing over and over. 'Lose weight.'

Barry's quote suggests that restrictive dieting can lead to physical cravings and feelings of dissatisfaction, potentially causing overeating later.

Barry: 'Suppose you eat little-half an Irish potato ... but you are craving in your body...you want to eat so much again ...you get up in night and eat- because your body is not satisfied.'

Theme 3. Indiscipline and entrenched dietary and lifestyle habits

Participants expressed challenges in maintaining discipline with diet and exercise.

Joseph: 'It is to do with discipline for me, I just cannot resist eating and ...all the things that they say create or cause the problem, ... I just feel bad because my discipline is terrible, with food and exercise, ...I shouldn't have that terrible indiscipline.'

Delroy: 'It is just discipline again. But I am telling the truth, I do not exercise. The exercise business, no, does not work for me.'

Delroy: '... the things that are most dangerous to people of color is sugar, salt and all the rest of it, and we flavor our foods [with them] all the time.'

Perceived individual and community needs

When asked to indicate what support participants needed for themselves and their community, the following themes emerged:

Theme 1. Need to have culturally relevant dietary information

A need for culturally relevant dietary information was suggested by all participants. The cultural relevance of dietary information available to them was suggested to be rather limited.

Rosa: 'It was you having to bring it [your food] into the conversation, which you always have to.'

Helen: 'I was sent to a diabetic training course which they tell you how to manage your diabetes, what to eat, how to eat, how to prepare it. So, it's basically diet and preparation [it was] generic...I just had to adjust it to what I eat.'

Theme 2. Need for information in accessible formats

Most of the participants expressed difficulty in obtaining, understanding and utilising health information. For

example, James (below) reported having limited computer literacy and general reading ability. He thus indicated greater reliance on non-literature-based information to self-educate about diabetes care.

Interviewer: 'What about diabetes education, did they send you on anything like that?'

James: '...I educate myself and I do my own thing, and it works with me. ... I'm fed up with the computer and with the technology as I can't [use] it.... It's a very big barrier for me. ...everything you have to go online, ... when I see a computer I just want to chuck it.'

Theme 3. Need for community-focused diabetes education and support

There was a request for local-level education and support initiatives, which participants noted had never happened in the community but felt would be a good forum for raising awareness and facilitating greater engagement (ie, participants are more likely to attend if invited by trusted people/community ambassadors).

Joseph: '...I have never had an opportunity, or me never interested in a anyway sitting like this in a room [to] talk about diabetes- never... I have never been part of any group that sits and has a conversation about diabetes in the black community.'

Joseph: 'If you utilize- what we call a community resource like here, and you say every month there is going to be a diabetic session at [hall] that's where you get people on board.... you need the people who [they] trust and know.'

Additionally, participants were keen for the researchers to return to feedback on the findings and to engage in initiatives to raise awareness and facilitate social support strategies.

Joseph: 'Yeah, come back again and let us sit down and have a reasoning because it is nice.'

DISCUSSION

This community-based qualitative study examined factors influencing healthcare-seeking behaviours and self-care practices among African-Caribbean individuals with diabetes living in southwestern England. The study explored barriers related to diet, physical activity and the utilisation of health services. A racially concordant community health champion, along with a researcher of the same background (PK-D), facilitated participant recruitment and data collection, allowing for the capture of rich data. While previous studies in the USA have demonstrated the effectiveness of such recruitment strategies,^{20 31} no comparable studies have been conducted within the African-Caribbean community in the UK.

Many of our findings are in congruence with those found in previous community-based studies. For example, Brown *et al*¹⁰ found that health beliefs, such as

perceptions of what constitutes healthy food and scepticism about prescribed medication, impact African-Caribbean people's self-management of diabetes. Our finding of 'perceived normalisation and acceptance of diabetes' suggests that there is an underestimation of the seriousness of the disease and its complications in this community. According to other studies, such an attitude can lead to poor self-management and engagement with health services. Notably, Muller *et al*³² reported that the acceptance of diabetes as normal within certain ethnic communities from the UK, Australia, Germany, Ireland and Taiwan contributed to poor self-management practices and low engagement with diabetes services. Similarly, Lawton *et al* found that South Asian communities often regarded diabetes as a manageable condition rather than a serious health risk affecting self-care behaviour.³³

Some of our participants expressed scepticism towards the concept of 'healthy eating' promoted in mainstream society, believing that much of the food available to them had been modified during production (eg, *grown inorganically with injections*) and was therefore unhealthy. This scepticism reflects findings from Ojo *et al* who reported that individuals from ethnic minority groups often mistrust mainstream dietary advice due to a perceived disconnect between modern food production and traditional methods.³⁴ Our participants also expressed frustration with the difficulty of accessing or affording their traditional foods, echoing similar findings by Satia *et al*, which examined how older people from the African-American community struggled to reconcile cultural food practices with the dietary advice they received.³⁵ A strong commitment to traditional dietary practice has also been noted among South Asian populations, where food choices are deeply rooted in cultural identity and valued for their perceived health benefits.³⁶

Regarding dietary advice, our participants reported that the information provided by healthcare practitioners often lacked cultural relevance, forcing them to adapt the general information they received. One participant in our study noted stereotyping, where healthcare providers assumed they consumed certain foods such as yam. This underscores the need for greater awareness among HCPs that newer generations of African-Caribbean individuals in the UK may not consistently follow traditional cultural diets. British-born, second and subsequent generations often adopt a hybrid diet, blending Caribbean and English foods, unlike older-generation migrants from the Caribbean. These evolving dietary patterns, which were not fully explored in this study, merit further research. It is crucial for healthcare providers to be aware of these changes, as newer generations may not adhere to traditional diets. Previous research has highlighted how younger generations often blend traditional and Western food practices, which can have distinct health implications.³⁷

Overall, our participants were more inclined to adhere to familiar traditional foods and avoid unfamiliar, tampered-with/modified foods. Addressing these views will no doubt be challenging as mistrust around dietary

messages is complex, inconsistent and may be influenced by factors beyond the messages themselves.³⁸

Scepticism about prescription medications also emerged as a significant issue in our study. Participants reported receiving mixed messages from healthcare providers and media sources, which fuelled concerns about the safety and efficacy of medications. This aligns with the findings of Peek *et al*, which reported mistrust in medical advice, particularly concerning diabetes medications in minority communities.³⁹ In some cases, the side effects of prescription medications were perceived as more harmful than the risks associated with diabetes complications. Some participants even described the doctors' prescribing of diabetes medication as 'experimental'. Similarly, Dixon-Woods *et al* found that perceptions of being a 'subject for experimentation' for medications are common among minority populations.⁴⁰ These concerns highlight the need for healthcare providers to foster open communication, enabling patients to make informed decisions and feel confident in their treatment. Prioritising patient-centred care could help improve engagement and trust, as demonstrated by Andersen *et al* and others who highlighted the positive impact of collaborative care models on diabetes management outcomes.^{41 42}

There was also evidence of low confidence and trust in HCPs and difficulty accessing healthcare services overall, a finding that resonates with broader research. For example, Blanchard *et al* noted that distrust in healthcare systems is a common barrier to care among Black and minority ethnic communities.⁴³ Participants in our study also felt unheard by their doctors, which may have contributed to a lack of trust in the system's ability to address their specific needs. The improved patient-doctor relationship is therefore imperative to address issues around the lack of trust in HCPs.

The use of herbal remedies among our participants reflects a broader preference for traditional treatments, as observed in other studies, such as Sriraman *et al*⁴⁴ and Chang *et al*.⁴⁵ These studies reported that herbal remedies are often seen as safer and more natural alternatives to pharmaceuticals, particularly in communities with a strong cultural attachment to traditional medicine. All participants who reported the use of herbs in our study were convinced of their beneficial outcomes. However, it remains unclear whether these perceived benefits are due to actual efficacy or the placebo effect, leaving the effectiveness of herbal treatments open to question. To prevent 'underground practices', as some participants admitted to concealing their use of herbs from doctors, patients should be encouraged to engage in open discussions with healthcare providers. Previous research has similarly noted a strong preference for herbal remedies in diabetes treatment among black Caribbean individuals.⁹⁻¹¹

Issues with self-discipline, such as difficulty maintaining regular exercise or resisting unhealthy foods, were identified as key barriers to diabetes self-management. Similar challenges have been reported in other groups, including South Asians and the white people.¹⁹⁴⁶ To enhance

diabetes self-management, interventions should provide personalised educational interventions that highlight the benefits of healthy lifestyle changes. According to Anderson's revised behavioural model, self-management is influenced by an individual's perceptions of their health condition, along with the interaction of socioeconomic, cultural and healthcare-related factors. This model highlights the importance of addressing these contextual factors to improve self-management behaviours.⁴¹ Implementing behavioural strategies focused on goal-setting and self-monitoring can empower individuals with diabetes to develop healthier habits.⁴⁷

A more in-depth analysis of our data revealed significant cultural and social factors affecting how black men and women perceive and manage diabetes differently. Male participants expressed greater distrust of HCPs, citing historical, personal and collective negative experiences, such as feeling 'unheard' or being 'instructed' by HCPs rather than being engaged in respectful conversations and were also associated with a general mistrust of authorities and people who from outside the community. Notably, disparities in health outcomes, between black men and women, have been attributed to differences in how they respond to actual or perceived healthcare discrimination, whereby discrimination is viewed as an environmental stressor that can lead to chronic health conditions.⁴⁸

In addition, among male participants' acceptance of diabetes as normal was more obvious, influenced by social interactions where younger men observe older men living with the condition without making significant lifestyle changes. This perception may lead many to underestimate the seriousness of diabetes, tolerate early symptoms of diabetes and continue unhealthy behavioural habits. As a result, men in their 40s and 50s may develop diabetes out of ignorance, increasing their risk of poor health outcomes. It has been shown that black women, of African and Caribbean heritage, have worse diabetes outcomes compared with men.⁴⁹ However, a more obvious 'normalisation and acceptance' of diabetes by our male participants might predict a reversal of that trend for the community we studied.

Our findings highlight a significant gender difference in the use of herbal remedies for diabetes management, with men relying more heavily on these treatments than women. This reliance may be influenced by a deeper mistrust of authorities and the healthcare system, compounded by poor diabetic health literacy, leading men to use herbal, often without prescribed medications, and male participants even travelling back to their native countries to obtain herbs. In contrast, women tended to research and integrate both herbal and medical treatments. Given these dynamics, improving healthcare outcomes for men requires more than just education; it demands a shift towards enhancing doctor-patient communication. By fostering trust and encouraging open, respectful dialogue, HCPs can better understand men's concerns, address their mistrust and explore how

herbal remedies might complement conventional treatments. This patient-centred approach promotes collaboration and cultural competence, ultimately supporting more effective diabetes management and better health outcomes.

The processes we undertook in the design, conduct and reporting of the study address Lincoln and Guba's⁵⁰ 4-item trustworthiness criteria for qualitative research: dependability, credibility, confirmability and transferability. First, the focus group topics were rigorously peer-reviewed and systematically executed during data collection. We used a semistructured format with eight clusters of predefined, open-ended questions. These questions were carefully designed to address the research questions and guide open discussions, allowing for spontaneous and in-depth responses from participants and the emergence of themes that researchers had not anticipated. To address issues of quality assurance, data were appraised against the topic guide research questions, aims and objectives after each focus group session. To improve the reliability, we used a collaborative approach to coding and analysis.⁵¹ Transcripts were first independently and systematically reviewed by the researchers, each using Braun and Clarke's methodology,²⁹ then collaboratively coded in NVivo and interpreted to identify the final themes, resulting in a process of researcher triangulation,⁵² which aimed to mitigate the potential for bias as PK-D and CL were 'insider' researchers. We identified recurring themes deductively, relating to the question categories and inductively identified pertinent themes within the spontaneous ideas expressed by participants. For confirmability, further member checking^{10 26} was used to corroborate interpretations. 'Outsider' researchers (RS, JR, SP) were able to question the insights arising from the data interpretations, and final interpretations were checked for credibility with participants in a feedback workshop, involving the original participants and other community members. For credibility in reporting findings, we provide quotes that illustrate how the themes were developed, derived from the data and aligned with the research questions.

The following points highlight the unique contribution of this study:

1. Our study uncovered important gender-specific differences in diabetes awareness, which could be crucial for improving the effectiveness of targeted diabetes educational intervention programmes. For instance, men were less aware (compared with females) of the seriousness of the disease, the need to reduce the carbohydrate content of their food, including portion sizes, and the importance of adhering to medical treatments. Furthermore, men also preferred (compared with females) to substitute prescribed medications with local herbal remedies such as bitters, aloe vera, cinnamon and Moringa.
2. Male participants, in particular, associated their general mistrust of authority figures (eg, police and government officials) with their reluctance to engage with healthcare services. They feared that healthcare providers might share their information with police and government officials, potentially exposing them to unwarranted scrutiny or interrogation.
3. Participants perceived medical advice given by their healthcare providers as largely 'experimental' rather than grounded in solid scientific evidence. This perception offers a unique insight into why members of this community may distrust the healthcare system.
4. Participants expressed scepticism about the healthfulness of foods marketed as 'healthy' in the UK, believing they were genetically modified, injected or chemically altered, and hence, less nutritious. This scepticism could limit their dietary choices.
5. Despite the mistrust of mainstream healthcare providers, participants expressed a strong interest in community-led diabetes education programmes, particularly if facilitated by trusted champions within their community. Involving community champions in the healthcare delivery system may improve the uptake of health services by African-Caribbean people.

Our study has some limitations. First, the transferability of our findings may be questioned, as data were collected from a specific region in southwestern England. While the study procedures are reproducible across different communities due to shared characteristics within the African-Caribbean population in the UK, such as migratory history, culture, transnational identity, socioeconomic status and sociohistorical experiences, the results may not be universally generalisable. Generalisability is inherently challenging in qualitative research as highlighted in a seminal paper by Lincoln and Guba.⁵⁰ Their work provides a useful recategorisation of 'generalisability' to 'applicability' when considering issues of rigour in qualitative research. While participants' views may vary based on their individual experiences within the specific community studied, our research adds to a growing body of knowledge that can be applied alongside findings from similar studies, to develop both targeted and broader solutions.

Second, corroborating our findings through multiple methods (methodological triangulation), such as one-to-one interviews and online surveys (data triangulation) and using an external audit,²⁷ to validate our interpretations would have further strengthened the transferability of our findings. While these strategies, including negative case analysis, are recognised in the literature for enhancing trustworthiness, practical constraints (as described in the Methods section), and resource limitations prevented their inclusion in our research design. Also, we did not collect information on the type of diabetic treatment that participants were receiving and lifestyle practices (smoking and physical activity), which would be more important in a quantitative study.

In conclusion, several cultural/community-related barriers were identified as significant factors influencing the health-seeking behaviours and self-care practices of black African-Caribbean people with diabetes in the UK,

some of which differed distinctly between male and female participants. Addressing these barriers is crucial for the development of effective, culturally tailored diabetes education programmes, or for the integration of culturally sensitive materials into the existing programmes, such as Diabetes Education and Self-Management for Ongoing and Newly Diagnosed and Dose Adjustment For Normal Eating.^{53 54} Furthermore, a patient-centred approach to healthcare services may foster open, honest conversations, encouraging patients to share their practices, while simultaneously enhancing the cultural competence of HCPs. Additionally, targeted, community-based education programmes, led by community members and utilising resources like community champions and media, could increase participation, particularly among younger generations of men who have not yet developed diabetes.

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