

# Perceptions of black African and African-Caribbean people regarding insulin

Helen Noakes

## Article points

1. Black African and African-Caribbean people are up to five times more likely than White people to develop diabetes and have an earlier onset of diabetes and its complications.
2. People's perceptions of insulin were influenced by health, cultural and religious beliefs, experience, beliefs about the health system and education.
3. Primary care professionals can reduce self-blame and psychological insulin resistance as a barrier to insulin treatment by educating people from diagnosis about the progressive deterioration of glycaemic control over time.

## Key words

- African-Caribbean
- Black African
- Insulin treatment
- Perceptions

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This qualitative study explores the perceptions among black African and African-Caribbean people with type 2 diabetes regarding insulin treatment. People's perceptions of insulin were influenced by four themes: beliefs, quality of life, the health system, and education. Psychological insulin resistance was present with underlying fear, worries and stigma about insulin commonly expressed. Most people taking tablets believed that insulin represented a worse stage of the condition with death imminent. In contrast, most insulin-treated participants held a strong belief in the efficacy of the treatment and how it prolonged life. Barriers that may prevent or delay black African and African-Caribbean people starting insulin need to be addressed through tailored educational interventions.

Early, intensively managed glycaemic control has sustainable long-term benefits in reducing microvascular and cardiovascular risk (UK Prospective Diabetes Study Group, 1998; Holman et al, 2008). The challenge remains in addressing the progressive deterioration of glycaemic control over time, since a stepwise addition of tablets, followed by early initiation of insulin, will be necessary for many people with type 2 diabetes (Wright et al, 2002; NICE, 2009).

Reluctance to initiate insulin has been termed "psychological insulin resistance" (PIR) and is recognised as barriers that prevent or delay treatment among people with diabetes (Polonsky and Jackson, 2004; Marrero, 2007). If insulin is required, diabetes is perceived as a more serious condition and believed to have progressed to a severe stage (Hunt et al, 1997;

Peyrot et al, 2005; Brown et al, 2007).

Ethnic disparities continue to exist in the management of diabetes, particularly among people of black African and African-Caribbean descent with type 2 diabetes. Millet et al (2007) observed that reduced insulin prescribing and less improvement in HbA<sub>1c</sub> was seen in these ethnic groups compared with the white British population. Resistance to prescribe insulin therapy among primary care professionals has largely been due to lack of support, confidence and experience (Jeavons et al, 2006), although the role of the community diabetes specialist nurse has developed to support insulin initiation in primary care (Shepherd et al, 2007).

Black African and African-Caribbean people are up to five times more likely than white people to develop diabetes and have an earlier onset of diabetes and its complications

(Diabetes UK, 2006). These communities represent nearly a quarter of the population in Lewisham, a deprived borough of South East London. Little research has focused on beliefs and attitudes about insulin among these black ethnic minority communities in the UK and how this may influence the uptake of treatment. Health beliefs, defined by McAllister and Farquhar (1992) as a person's beliefs about health or illness and exposure to health promotion, appear to have a major impact on black African and African Caribbean peoples' adherence to their diabetes treatment (Brown et al, 2007).

The aim of this study was to explore perceptions of insulin treatment among black African and African-Caribbean people with type 2 diabetes, to gain insight into the barriers to treatment and strategies to overcome resistance. The study was not designed to establish differences between these ethnic groups.

### Methods

A qualitative study was conducted using two focus groups: one for people with diabetes treated with tablets ( $n=7$ ), the other for those treated with insulin ( $n=6$ ). Focus groups were preferable to one-to-one interviews because participants are less influenced by the interaction with the researcher. They also provide a social context within which spontaneity arises, as hearing the views of others can trigger responses (Gillham, 2005). Ethical approval and research governance was granted (Department of Health, 2004) in March 2006 and written informed consent was obtained immediately before the focus groups started. Participants were recruited from diabetes outpatient clinics at a South London NHS hospital Trust (*Table 1* summarises the exclusion and inclusion criteria for the study). This purposive sampling reflected the diversity of the population from practices that referred to the clinics.

Posters were displayed in clinic rooms and the reception area of the diabetes unit for people to self-evaluate their suitability for the study. Healthcare professionals discussed the study in more detail during the clinic if an individual expressed an interest, and an invitation pack was given. The recruitment process lasted 8 weeks, during which 30 packs were distributed prior to enrolment for the study. The packs included an invitation letter, information for participants and a reply slip with a prepaid addressed envelope to the researcher. On receipt of a signed reply slip, a confirmation letter was posted to participants and a telephone call made by the researcher a week before the focus group as a reminder. Participants were not known to the researcher who conducted the study.

The focus groups lasted an hour and were conducted in a private room in the education centre at the author's NHS Trust. They were recorded, transcribed and analysed using

thematic content analysis. The researcher asked questions from an interview agenda (Table 2) and an observer was present to make notes on non-verbal cues during the discussion. Travel expenses were reimbursed.

**Table 1. Exclusion and inclusion criteria for the study.**

<i>Inclusion</i>	<i>Exclusion</i>
<ul style="list-style-type: none"> <li>● Black African/African-Caribbean adults with type 2 diabetes.</li> <li>● English speaking.</li> <li>● Treated with oral antidiabetes tablets or insulin.</li> <li>● Diabetes care received in Lewisham.</li> </ul>	<ul style="list-style-type: none"> <li>● Black African/African-Caribbean adults with type 2 diabetes who attend the researcher's clinics.</li> <li>● Non-English speaking people with type 2 diabetes.</li> <li>● Type 1 diabetes.</li> <li>● Children and adolescents.</li> <li>● Diabetes during pregnancy.</li> </ul>

**Table 2. Focus group interview agenda.**

1) What comes to mind when I mention insulin?
2) Why do you think some people with type 2 diabetes might need to have insulin?
3) What do you think the benefits of having insulin are?
4) What worries or concerns "would you have if" (for those on tablets)/"did you have when" (for those on insulin) you were told you needed insulin?
5) What do you think has influenced your views about insulin treatment? <i>Prompts: What are the beliefs about insulin in your community? Where do these beliefs come from – family, religion?</i>
6) How do you think you would be treated by other people if you needed insulin?
7) Do people within your communities know enough about insulin treatment for type 2 diabetes? If no, what ways could awareness and knowledge be increased about insulin treatment for type 2 diabetes? <i>Prompts: Groups sessions, individual consultation</i>
8) What sorts of information should be included?

**Table 3. Participant characteristics.**

	Tablet group (n=7)	Insulin group (n=6)
Age range (years)	44–77	53–69
Mean	62	60
<b>Ethnicity and gender</b>		
– African, female	3	2
– Caribbean, female	2	1
– Caribbean, male	2	3
Duration of diabetes (range)	4 months to 11 years	4 to 26 years
Duration on treatment (range)	4 months to 10 years	5 months to 22 years

**Data analysis**

Transcripts were printed on different coloured paper to allow easy identification of the original source during the analysis process and to purposively make comparisons between the tablet group and the insulin group (Green and Thorogood, 2004).

A coding system was used to help organise the data and transcripts were annotated in margins with categories that emerged. Sections were cut out and rearranged on a wall covered with flip chart paper. Categorisation was reviewed until the researcher was sure that emerging themes and categories accurately reflected the data.

**Results**

Twenty people volunteered to be involved in the study. Four subsequently declined for different reasons: two due to a schedule conflict, one because of family bereavement and one had difficulty with transport. Three did not attend on the day. Therefore, 13 people participated in total, seven for the tablet group and six for the insulin group (Table 3).

Perceptions regarding insulin were influenced by four main themes: beliefs, quality of life, the health system and education (Table 4). Quotations are classified by treatment group (tablet, insulin), ethnicity, and gender (African female [AF], Caribbean female [CF], Caribbean male [CM]).

**Theme 1: Beliefs**

*Health*

Some participants in the tablet group believed that insulin had more severe side-effects than tablets, having witnessed a relative experiencing a hypoglycaemic episode and becoming "mentally deranged" (AF, tablet group). Most talked about insulin representing a worse stage of the condition, an indicator that the diabetes was more severe and how black people view insulin as a death sentence:

*“We have all been programmed that insulin is the last resort. So you think, oh my God what does that mean, am I getting nearer to death?”* (AF, tablet group).

By comparison, all participants in the insulin group believed that insulin therapy prolonged life.

### Religion

Participants in both groups strongly believed there were black people in their community who would refuse insulin, leaving their destiny to nature and prayer alone:

*“I know there is people that would say they can’t do insulin because they say they would rather God help them.”* (CF, insulin group).

Both groups held the belief that “God helps those who help themselves” (AF, insulin group) and justified self-care and the healthcare professional’s role in their treatment by discussing how God works through others:

*“God provides doctors, nurses and physicians to help people ... Whatever the doctor or nurses prescribed is helped through God’s mercy. Sometimes it not helps everybody, but God isn’t in control of these things ... As far as he concerned, God helps me through them.”* (CM, tablet group).

### Culture

Participant’s perceptions of insulin were influenced by cultural beliefs and attitudes towards illness and treatment. Most people in the tablet group expressed how black people do not talk about diabetes as there is much stigma and taboo attached to this condition and insulin use. Participants of African descent in both focus groups talked about how people in their community were secretive and proud, suffering illness in silence:

*“The reason why my mother suffers with it, is that she is a very conservative, proud woman. She finds it hard to tell people she’s on insulin.”* (AF, tablet group).

These attitudes to illness appeared to be influenced by traditional upbringing in Africa and the Caribbean:

*“Being able to accept the illness that is where the black thing comes into it ... it’s so difficult to try and change a black person ... Once they adopt a way of life it’s difficult to drop it.”* (AF, tablet group).

Some believed black people would feel ashamed to disclose they took insulin:

*“Some people don’t believe in washing their dirty linen outside!”* (AF, tablet group).

### Knowledge and understanding

Some participants in the tablet group were concerned about insulin’s unnatural constitution and the likelihood of having an “allergic reaction to the needle” (CM, tablet group). Most wanted to know about the “ingredients in insulin” (AF, tablet group) and would want an allergy test prior to taking it. Most in the insulin group had a good understanding of the benefits of insulin from personal experience. Overall there was a lack of knowledge about what the HbA<sub>1c</sub> level represents, with different views about when to self-monitor blood glucose and little understanding of what to do with the results.

Some in the insulin group confessed to greater indulgence in foods they would have restricted when taking tablets, believing the insulin would control the glucose level, while others remained cautious about foods eaten:

*“With the insulin I eat ANYTHING.”* (AF, insulin group).

*“I’m still cautious what I eat like.”* (CM, insulin group).

*“Yeah but sometimes I taste a little thing what I know I don’t supposed to really eat ... You can eat everything but small amount of it.”* (CF, insulin group).

One participant in the insulin group offered sweets to the group; three accepted and ate them during the group discussion.

### Page points

1. Participants in both groups strongly believed there were black people in their community who would refuse insulin, leaving their destiny to nature and prayer alone.
2. Most people in the tablet group expressed how black people do not talk about diabetes as there is much stigma and taboo attached to this condition and insulin use.
3. Some participants in the tablet group were concerned about insulin’s unnatural constitution and the likelihood of having an “allergic reaction to the needle” (CM, tablet group).

**Table 4. Themes and categories that emerged from the focus groups.**

<p><b>1. Beliefs</b></p> <ul style="list-style-type: none"> <li>● Health.</li> <li>● Religion.</li> <li>● Culture.</li> <li>● Knowledge and understanding.</li> </ul>
<p><b>2. Quality of life</b></p> <ul style="list-style-type: none"> <li>● Control.</li> <li>● Coping.</li> </ul>
<p><b>3. The health system</b></p> <ul style="list-style-type: none"> <li>● The system.</li> <li>● Doctor–patient consultation.</li> </ul>
<p><b>4. Education</b></p> <ul style="list-style-type: none"> <li>● The community.</li> <li>● The message.</li> </ul>

**Page points**

1. All participants in the insulin group expressed how insulin controlled their blood glucose levels better than tablets.
2. Some in the tablet group were worried about living alone, not being able to cope should they experience a hypoglycaemic episode, which was a concern reinforced by some in the insulin group.
3. In both groups, most talked of the healthcare system in Africa and the Caribbean and how it disadvantaged people with diabetes who were unable to afford treatment.
4. The doctor's role was highly respected and seen as powerful, knowledgeable and influential in decision-making.

Poor diet, lack of exercise and being overweight were reasons cited by some in the tablet group for people requiring insulin, while others understood that these factors cause the body to stop producing enough insulin. In both focus groups, some reported having tried their best to avoid insulin, attributing self-blame for running high blood glucose levels, by straying from the diet or not taking enough exercise.

**Theme 2: Quality of life**

All participants in the insulin group expressed how insulin controlled their blood glucose levels better than tablets. For some it had improved their quality of life by alleviating symptoms.

All participants in the tablet group believed the tablets and their lifestyle controlled their diabetes without the need for insulin. Both groups agreed that their glucose level needed to be controlled to avoid diabetes complications, including blindness, kidney damage and heart attack.

**Coping**

For most people in the insulin group, responsibility for altering the insulin dose was given to the nurse or doctor. Some in the tablet group expressed concern about how they would regulate the dose of insulin with daily activities if they took insulin. Others in the tablet group were worried about living alone, not being able to cope should they experience a hypoglycaemic episode, which was a concern reinforced by some in the insulin group:

*"I think it's rather dangerous for a diabetic to be on his or her own you know, because I find that when I go into hypoglycaemic, sometimes it's a struggle to maybe get to the kitchen."* (CM, insulin group).

Coping responses were driven by underlying feelings of fear, and many in the tablet group shared views about people in their community having a fear of needles and injections:

*"Black people have difficulty understand the importance of insulin due to the fear factor of needles, some of them are so scared of giving themselves insulin."* (AF tablet group).

Others in the insulin group expressed acceptance of insulin treatment prior to taking it and talked of "living with it" (CM, insulin group). This acceptance of treatment was reiterated by only one participant in the tablet group:

*"If you have diabetes, don't let it take over your life. You live your life around it and accept it of your medication and get on with your life."* (CF, tablet group).

**Theme 3: The healthcare system**

Uptake of insulin treatment was influenced by the healthcare system and the doctor–patient consultation.

**The system**

In both groups, most talked of the healthcare system in Africa and the Caribbean and how it disadvantaged people with diabetes who were unable to afford treatment. Most in the insulin group acknowledged this as a barrier to starting insulin for those people in their native country. One participant in the insulin group described how family members in Jamaica had died young from diabetes complications as they could not afford to pay for insulin and blood glucose monitoring equipment:

*"We accept [insulin] because we can get it but what about people who cannot get it, they don't give it to them free, they have to pay to get the injection. And it's expensive and you have to keep it in the fridge. In Jamaica some people don't even have a fridge in the house."* (CF, insulin group).

**Doctor–patient consultation**

There was general agreement in both groups of the value of a check-up and to have a consultation with a doctor or nurse who understands diabetes. The doctor's role was highly respected and seen as powerful, knowledgeable and influential in decision-making.

In the tablet group, some people reported how the doctor had used insulin as a threat to try and encourage lifestyle changes:

*“I know several times the doctor told me your sugar is up, your sugar is up and he said it has to come down or else we put you on the insulin. I’ve been dreading that.”* (AF, tablet group).

#### Theme 4: Education

Education focused on the community and what the message should entail to promote greater awareness and understanding about insulin therapy.

##### *The community*

Both groups agreed that people of black African and African-Caribbean descent did not know enough about insulin treatment and its benefits. Most believed that education should be targeted specifically at the community through surgery clinics, church groups, community events and organisations, schools, group discussion sessions (such as the local Diabetes UK group) and the media through relevant TV and radio stations and websites. This would present an opportunity to share experiences and reach out to ordinary people.

##### *The message*

Most participants in the tablet group felt strongly that the educator should be someone with diabetes taking insulin, preferably of the same ethnic origin, as this would help to motivate and connect with the people:

*“They’ll welcome you more because they will see you as one of theirs and you’re not likely to lie to them, you know ... And because of that culture thing whereby they don’t open up enough to see their own kind being open they will feel relaxed.”* (AF, tablet group).

All participants in the insulin group wanted the educator, regardless of ethnic origin, to be a healthcare professional who was knowledgeable about diabetes, direct and plain-speaking to motivate people. Both groups agreed the educator would need to understand about traditional foods and encourage a reduction in the quantity eaten:

*“Because we have a lot of food isn’t it. We have garri, we have pounded yam, we have rice, we have amala, plantain, fufu. We don’t know the calories. We just eat.”* (AF, tablet group).

There was a strong message from all in insulin group that insulin did not mean you were dying, there was nothing to be ashamed of, and regulating the dose along with injection sites were all a package of education:

*“Insulin is very good, it saves life.”* (AF, insulin group).

*“You need to be educated to do it correctly. It can really help.”* (CF, insulin group).

Giving the injection was not considered difficult and most expressed it was not painful:

*“Let people realise that having insulin is just as easy as having the tablet. Before, I did not think that.”* (CM, insulin group).

Some participants expressed that if people knew they had high glucose levels earlier, rather than wait until they were really sick, the education and treatment could start sooner. However, it was commented that this would require black people to:

*“Drop the proud attitude and go regularly for check-up!”* (AF, tablet group).

#### Discussion

People’s perceptions of insulin were influenced by health, cultural and religious beliefs, experience, beliefs about the healthcare system and education. People treated with insulin held a strong belief in the efficacy of this treatment and how it prolonged life, compared with those taking tablets who believed that insulin represented a more severe stage of the condition with death imminent.

Religion played an influential role in participant’s decision-making, justifying self-care and the healthcare professional’s role in treatment, although there was acknowledgement that some people within their community would refuse

#### Page points

1. Most people believed that education should be targeted specifically at the community through surgery clinics, church groups, community events and organisations, schools, group discussion sessions (such as the local Diabetes UK group) and the media through relevant TV and radio stations and websites.
2. All participants in the insulin group wanted the educator, regardless of ethnic origin, to be a healthcare professional who was knowledgeable about diabetes, direct and plain-speaking to motivate people.
3. People treated with insulin held a strong belief in the efficacy of this treatment and how it prolonged life, compared with those taking tablets who believed that insulin represented a more severe stage of the condition with death imminent.

### Page points

1. Barriers to insulin initiation were fears of needles, self-injecting, episodes of hypoglycaemia, weight gain, along with worries about living alone and regulating the correct dose of insulin.
2. In general, knowledge and understanding about diabetes was low. Feelings of self-blame and guilt when blood glucose levels ran high were openly expressed, and these feelings have been associated with greater worry about switching to insulin.
3. Education should be delivered not only from healthcare professionals with expertise in diabetes, but from black African and African-Caribbean people treated with insulin, to help motivate and connect with people who may require this treatment in the future.

insulin, leaving their destiny to nature and prayer alone. People who harbour these beliefs appeared to be influenced by particular religious groups.

Barriers to insulin initiation were fears of needles, self-injecting, episodes of hypoglycaemia, weight gain, along with worries about living alone and regulating the correct dose of insulin. The people of black African descent in this study expressed how people within their community were very proud and some would be secretive about disclosing that they took insulin due to the stigma attached. Similar to Brown et al (2007), people taking tablets worry about the unnatural constitution of insulin and the effect it may have on the body. Acceptance of insulin was associated with personal experiences of the benefits, and having coping strategies of sharing the experience with family and friends.

In general, knowledge and understanding about diabetes was low. Feelings of self-blame and guilt when blood glucose levels ran high were openly expressed, and these feelings have been associated with greater worry about switching to insulin (Peyrot et al, 2005). There was a lack of understanding about the HbA<sub>1c</sub> measurement, the progressive nature of diabetes and the likelihood of some people requiring insulin in the future.

The approach of some doctors was to use insulin as a threat to improve treatment adherence and glycaemic control and this merely magnifies the issue of PIR (Polonsky and Jackson, 2004; Marrero, 2007). Generally, positive experiences were relayed about the importance of a diabetes check-up and consultation with a healthcare professional who understands about diabetes and traditional foods used in the diet.

There was overall recognition of the lack of knowledge and understanding about insulin treatment for people with type 2 diabetes and the need to educate the wider community to allay fears and misconceptions. These findings suggest that education should be delivered not only from healthcare professionals with expertise in diabetes, but from black African and African-Caribbean people treated with insulin, to help motivate and connect with people who may require this treatment in the future. Health, cultural and religious beliefs

about insulin should be incorporated into structured education programmes.

### Validity, reliability and limitations

To enhance validity, two colleagues – an African-Caribbean dietitian and African lifestyle assistant – helped with cross-checking and clarification of sections of transcript for accuracy. Responses may have been influenced by whether participants were born either in the UK, Africa or the Caribbean as there are differences in the healthcare systems.

As this study involved a small sample, black African and African-Caribbean people were in the same focus group with genders mixed.

The diagnosis of diabetes, duration on treatment, current glycaemic control (HbA<sub>1c</sub> level) and the presence or absence of diabetes complications may all have influenced responses from participants.

Those taking insulin had different recollections of starting insulin as they were retrospectively reflecting on their experiences. By comparison, participants on tablets were prospectively relaying views about taking insulin in the future, which may account for some differences in the group responses.

The findings may not represent individual perspectives as focus groups do not always allow equal participation of all group members. Individuals may also be influenced by the views of others in the group. As all participants were English-speaking, their views may not represent the community from which they originate.

### Conclusion

Educational interventions need to raise awareness within the community and target people from black ethnic communities who have type 2 diabetes. This research may enable primary care professionals to understand more fully the reactions of black African and African-Caribbean people towards insulin and the value of the diabetes consultation to explore and overcome negative beliefs and attitudes.

Primary care professionals can reduce self-blame and PIR as a barrier to insulin treatment by educating people from diagnosis about the progressive deterioration of glycaemic control

over time. Fears and resistance to insulin among people from these minority ethnic communities need to be addressed if treatment is to be given early to avoid the increased risk of complications.

Future research could explore and compare the views towards insulin of black African and black Caribbean people with type 2 diabetes. This may help to identify attitudes and beliefs about insulin that require joint educational intervention, including other ethnic groups and those that require culture-specific interventions. ■

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***“This research may enable primary care professionals to understand more fully the reactions of black African and African-Caribbean people towards insulin and the value of the diabetes consultation to explore and overcome negative beliefs and attitudes.”***