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Lay Perceptions about Tuberculosis among Non-UK-Born Black Africans in the United Kingdom

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Abstract

Background: Tuberculosis among non-UK-born Black Africans has been gradually recognized as a public health problem in the UK despite the various interventions implemented. Objectives: To explore the perceptions of non-UK-born Black Africans about TB health risk; to explore the health seeking behavior of the non-UK-born Black Africans in relation to TB and to explore lay views on TB health education and screening as opportunities for health promotion. Methodology and Study Design: A qualitative methodology was used on a purposively selected sample of 12 non-UK-born Black Africans living in Leeds. Face-to-face interviews were conducted to explore the lay perceptions about TB. Thematic analysis was used to derive important themes in accordance to the study objectives. Ethical approval was provided by Leeds Metropolitan University. Setting: Community setting of non-UK-born Black Africans in Leeds, UK. Results: This population holds mixed views and perceptions about tuberculosis, few facilitators and many barriers existed to current TB prevention efforts. The barriers included: language barriers, barriers related to services and systems, immigration status and stigma despite the benefits involved. The potential for black African communities to readily increase the likelihood of behavior change was found as an important finding for this study. Conclusions: Tuberculosis is a preventable public health problem. Involvement of the non-UK-born black Africans communities in the TB prevention may be beneficial for reducing and tackling TB rates in this population. Such an approach is potentially inexpensive and more readily implementable than other suggested strategies such as changes to immigration policies.

Keywords

Non-UK-Born Black Africans, Tuberculosis, Risk, Help-Seeking Behavior, Screening and Health Education

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#Ruth Cross supervised the study and contributed to study design.
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1. Introduction

Globally, approximately two billion people are infected with tuberculosis (TB). 1.7 million people die each year and nine million people are newly diagnosed with TB annually [1]. Most cases occur in sub-Saharan Africa [1] where HIV infection, a major risk factor for TB is most prevalent [2]. The United Kingdom had the highest TB prevalence [3] and incidence rates in Western Europe at 15/100,000 populations with a 4.2 percent increase incidence in 2009. These figures translated to 9040 cases in that year, of which 5871 cases were non-UK-born [4]. The prevalence rate among the non-UK-born is 20-fold higher compared to those born in the UK at 88/100,000 populations versus 4/100,000 populations, respectively [4]. Among the non-UK-born, black Africans are among the ethnic minority groups with the largest proportion of TB cases in the UK at 1574 of 5871 (27%) of cases [4]. The high prevalence has been attributed to high TB rates in their host countries, HIV co-infection [2], the migration patterns, [5] living and working conditions, and poverty in the UK [6].

In general, health-seeking behaviors among black Africans are typically poor [7] [8]. Such behaviors may be due to a lack of information and appreciation of outcomes, which might be understood through the Health Belief Model (HBM; see **Appendix Figure 1**) [9]. According to the HBM, people are likely to change a given behavior or attitude if they consider the outcome of their actions as severe [10]. In the case of health promotion, people need to first acknowledge that a health risk applies to them before engaging in a protective behavior [11]. For example, people must consider the illness as serious and consider themselves as susceptible to the illness before they feel motivated to respond to health promotion interventions. People may then engage in interventions if they consider themselves capable to have protective behavior and if the behavior is associated with reduced health risk [12]. This belief then influences their decision to seek help and respond to health promotion interventions [13].

A given belief, however, may not necessarily lead to performance of the health behavior based on different types of modifying factors, including demographics, socio-economic and availability of information [14] [15]. For instance, an individual may have a poor understanding of what could be done to support the preventive behavior. These modifying factors within the HBM may be important for predicting and explaining how they ultimately behave [16] and the likelihood of action depends on the individual's analysis of the costs and benefits. Prior work has shown that economic benefits and social rewards often weigh more heavily than health gains [17], and thus all of these factors warrant consideration.

To explore lack of TB health seeking behaviors among black Africans in the UK, we conducted in depth qualitative interviews of recent immigrants, eliciting their perceptions of TB health risk, benefits and barriers to seeking help, and TB health promotion opportunities.

2. Methods

2.1. Participants

Participants were non-UK-born black Africans aged >18 years living in Leeds, England for 1 - 5 years. Adults with no clinical symptoms of TB were included in this study to explore the participants' perceptions about TB rather than experience with TB. However no tests were performed to confirm the lack of a TB diagnosis. All participants were able to speak English, as financial constraints did not allow for interpreter. Purposive sampling was used to identify study participants from the community. Specifically a community engagement officer who deals with African communities for HIV/AIDs prevention in Leeds was contacted for assistance to gain access and recruit the participants. He indentified four individuals at an African community gathering during a community health education session. Snowball sampling was then employed to identify additional participants. The study objectives were explained to each study participant and interviews scheduled.

2.2. Data Collection

Semi-structured qualitative interviews were used to explore the participants' perceptions about TB. The interview guide with open-ended questions was developed based on the research objectives and literature [12] [14]. It was then pre-tested to ensure clarity among non-UK born black Africans who were not included in the formal sample. The interviewer first obtained socio-demographic information as highlighted in **Appendix Table 1**. A vignette about being diagnosed with TB was then presented, and this encouraged the participants to provide their opinions about the topic. The interview focused on three main areas: 1) perceptions of TB health risk; 2) benefits and barriers to seeking TB care; and 3) TB health promotion opportunities. Probes were used to obtain clarity,

enrich and obtain detailed information [18]. The interviews lasted approximately 45 minutes each. The study was conducted and carried out by the first author in Leeds city, UK.

2.3. Analysis

Interviews were audio-recorded and transcribed for data analysis. Thematic analysis was used. In line with [19], thematic analysis was used to understand TB seeking behaviors due to its ability to report participants' events, reality and making meanings out of them. All the interviews were initially reviewed to generate codes, which were compiled as a codebook. The codebook was then used to group codes and form basic themes, which were arranged to form the organizing themes and ultimately global themes. The outliers were then eagerly explored to add richness and robustness to the themes, and the results summarized under the generated themes. Interviews were conducted until thematic saturation was achieved. This process was manually conducted.

2.4 Ethical Approval

This project was reviewed and approved by Leeds Metropolitan University Institutional Review Board.

3. Results

3.1. Participants

A total of 15 individuals were contacted, of whom 12 accepted to participate in the study. Three participants declined due to time constraints. Seven participants were males and five females. Participants were aged 18 - 49 years.

3.2. Key Themes

Four themes were identified: 1) Accuracy of TB knowledge, risk perception, and the need for screening is mixed, 2) Free access to health services and attainment of health are facilitators of TB health seeking behavior, 3) TB screening and care are limited by both individual and system-level barriers, and 4) the black African community can best reach black Africans to promote TB health seeking behavior.

1) Accuracy of TB knowledge, risk perception, and the need for screening are mixed.

The level of knowledge about TB was mixed. TB was generally known to be contagious; however, some participants incorrectly believed that it could be acquired through touching someone.

"*...because it is highly infectious… so if you sneeze without covering your mouth the germ can be passed to the next person.*"

"*Sometimes tuberculosis is spread from one person to another if one person is infected and the other one is not infected. If a person with TB touches you, you can get it. That's how most people back in Africa get it because most of them have it and they like hugging and shaking hands*".

The biological and environmental factors that cause tuberculosis were mentioned, although misconceptions about disease causation existed.

"*Sometimes like for myself I am asthmatic and was born with asthma. Sometimes I understand that if you are not born with asthma and you get it and you don't seek treatment in its early stages, you may develop tuberculosis...*"

"*I think there must be a reason to get TB because the environment we are in here is different from that in Africa. In Africa, there is a lot of dust and here the environment is clean and safe, so I don't think we are at risk*".

Some participants identified TB as a disease that is acquired through the sexual route.

"*…or may be could be through sexual intercourse, …I am looking at the person who has got TB and he gets into contact with another person, maybe a lady. And then through that act of sex and that act of being close to each other intimacy and so, then the TB will be spread from this person to the other one*".

Most indicated their susceptibility to TB arising from their origins in Africa, where the prevalence is high. They recognized the increased risk for TB due to the concurrent high prevalence of HIV/AIDS in Africa.

"*…birds of the same feathers flock together… Naturally most of our friends are from Africa where TB cases are high, so the chance of getting it would be higher among the Africans, which would probably account for a high rate of it among the blacks*".
"*...because HIV is high in Africa and a lot of people are here and they have it, so their immunity is low. So if they come into contact with whatever causes TB, they can contract it.*"

This ambiguity in knowledge was also seen in the importance of screening. Participants stated the importance of screening to reduce the risk to TB, but reported not receiving screening.

"*…Screening for instance is important because it can help the black people that have the disease to get treatment. I don't know much, but for me when I was coming here, I was not screened and have never been screened for that disease*."

2) Free access to health services and attainment of health are facilitators to TB seeking behavior.
Participants identified attaining good health and avoidance of TB disease as facilitators for seeking help and responding to TB health promotion opportunities. Free health services and medication encouraged participants.

"*…Because I don't want to get the disease. The hospital here is free and there is good medication…so I would seek help if I need to. Financial problems may affect me to seek help but here the medical services are free*."
"*Because I don't want to get sick so I don't like coughing in public any way. That's why I would be motivated to go and get tested. As you know TB can damage the immune system and you become weaker...*"
"*...My health would really motivate me because I have to make sure I have good health. And then avoiding contaminating other people with tuberculosis*".

3) TB screening and care are limited by both individual and system-level barriers.
Individual barriers focused on stigma and, limited communication, while system-level barriers arose from immigration and healthcare delivery systems.
TB stigma was evident among some participants who perceived TB as linked to HIV infection; that everybody with TB also has HIV which increases TB stigma and limits care seeking and TB screening.

"*Because you know TB, it is HIV related so if you get TB people will be suspecting you to have HIV. So when they talk about TB, they can brand you with AIDS because you have TB. So People suffer that branding and will always suffer and not go for the services*".

English was associated with communication problems as a barrier to help seeking and a hindrance to health promotion opportunities. The British accent was also a challenge.

"*...Language is very important because not everybody can read and write English some still don't read and write and therefore the information is common in leaflets and they may not get anyone to read and explain it for them. Even though they have got the information in their hands... they will still be ignorant.*"
"*The language barrier is very clear because doctors... have very difficult English which I can't understand. This can lead to giving wrong information or even fear going for the health services*."

Immigration status acted as a barrier to seeking TB help due to discrimination, denial of a visa, and fear of being deported. To avoid these fears, participants avoided seeking TB help.

"*There have been stories of many people being screened and if they are found to have something (meaning TB) they are denied visas. And because you are desperate to get a visa, you don't want something that will act as a barrier to your coming and being here*."
"*If you are not allowed to stay in this country, you are not authorized by the home office. Then if you are in that category, you are not going to get TB help.*"

Barriers related to systems in healthcare service delivery included: costs, long distances and complex processes in accessing services.

"*Because you know here there are many difficult systems involved... so having come to the foreign country it takes time for one to be accustomed to these many systems. So unless you have someone directing you, you would not know where to go for TB help...*"

"*There is a long process one goes through before accessing TB help. One need to make appointments and then you are given the date and time of seeing the doctor. This takes a long time.*"

Participants stated that the government needed to make TB a priority. They felt more emphasis was placed on other health issues, such as lung cancer and HIV, and expressed a need for the government and other stakeholders to support TB programs to curb the disease.

"*Instead of saying prevention is better than cure, the government should come out higher to sponsor TB programs… they have to come out openly and alert the population...*"

4) The black African community can best reach black Africans to promote TB health seeking behavior.

Participants felt that black African communities could be leveraged to promote TB health seeking behavior, specifically through effective and acceptable information provision.

"*Through the community especially because here, there is a community, for example the Somalia community, the East African community, the Ugandan community. The government should follow those specific communities to give them information…*"

They felt that black Africans could be of great benefit to tackle the issue of language and limited TB information. They could then train other black Africans to pass on TB information to reach their communities and overcome the barriers.

"*I think if the black Africans are trained in the TB health education, they will be able to pass on information to their Blacks in a more acceptable way.*"

Avenues for creating awareness included mass media and black Africans' community gathering with particular focus on churches.

"*...Here in UK, the government uses TVs and radios to give information to the people and yet people are never in their homes. What needs to be done is the government needs to come out and meet the black Africans in their gatherings... in their places of worship as most Africans like going to church.*"

"*You know most Africans living here in the UK live like communities, in their community groups, just penetrate those community groups and talk to them. Go to the religious leaders because most of us belong to these churches.*"

4. Discussion

In this qualitative study of non-UK-born black Africans, we found with mixed accuracy in knowledge, perceptions about TB risk, barriers and relatively few facilitators for TB health promotion opportunities. Importantly, however, participants identified the potential for black African communities to encourage TB health-seeking behavior amongst themselves.

These findings can be well explained by the HBM in which individual perceptions influence the likelihood of action. Our findings suggest that limited information about the disease could put individuals at risk of TB or hinder help-seeking and participating in TB screening [20]. Other studies have also reported limited knowledge about TB among ethnic groups in the United Kingdom and elsewhere [21] [22]. Although participants acknowledged some susceptibility to TB, they did not express a high degree of perceived threat. A cue to action would therefore be needed to lead to behavior change. Education with accurate information is logically critical in overcoming misperceptions and plays a vital role in TB prevention and control for effective response to TB health promotion opportunities [21].

The mixed understanding of risk and the need for screening points to the complexity of risk. People understand risk differently; what may be considered worth avoiding and high risk for one person may be different for another. Moreover, understanding risk lies within individual's social and personal context and beliefs [13]. Perception of risk depends on disease outcome and its magnitude of personal threat. Health promotion interventions that are centered towards TB risk perception and prevention need acknowledgement in education as another cue to action. The greater the risk perception, the higher the likelihood of action to engage in the positive behavior change, thus leading to decreased risk. While inherent degrees of risk aversion or tolerance are difficult to change [23], tailoring education to an individual's perception of risk may increase TB screening and response to

health promotion opportunities. In this study, as well as others in Canada and Europe [24] [25], most participants highlighted TB screening as a means to reduce the risk and curb TB, but did not seek screening. However, people are more likely to seek help or go for screening if they consider themselves at risk of getting TB [11].

System-level barriers were identified as a modifying factor for TB health-seeking behavior in this population. A potential solution for these barriers that arose from this study was optimization of immigration policies. For example, TB screening could be conducted on entry to the country with a guarantee that it would not prevent immigration; linkage to free care would also be important. This was a surveillance system to allow identification of immigrating populations that are at a risk of TB compared to the general population. Such policies would facilitate seeking help for TB. Additionally, community engagement and mobilization can support or catalyze the likelihood action for positive change. [17] found that when people are confronted with socio-cultural and structural barriers to access TB care, medical knowledge and awareness alone cannot effectively promote ideal practices. He suggests that communication programs need to adopt a ‘‘social rationality’’ perspective based on understanding of community experience of TB.

An important finding of this study is the potential for black African communities to readily increase the likelihood of behavior change. Communities need to be empowered to take control over their own health and health-seeking behavior; excellent opportunities for community engagement include community gatherings, like parties, country specific meetings and church services. The church community setting has been found appropriate in promoting health and raising awareness among the black immigrants elsewhere [26]. Prior work has shown that TB health education can be effective if health promotion practitioners create a supportive environment and understand the cultural barriers [8]. The use of community lay workers is vital at increasing screening coverage and reaching the hard to reach black communities [27]. Community-based programs help people become active participants in improving their health and wellbeing, rather than acting as passive recipients of professional efforts [28]. Inaccessible TB health promotion services, such as the current efforts in the UK, do not effectively promote health behavior. Non-UK black Africans may be willing to respond to health promotion opportunities in the community, but barriers may outweigh the benefits involved. Services need to be brought closer to the people in their communities, thereby overcoming many of the barriers identified such as English language, fears of immigration policy. This was also noted by Joffe [23].

Additionally, health promotion messages and information need to be designed and tailored to meet the needs of the targeted population; engagement with relevant African beliefs and lay perceptions about TB could be a powerful motivating approach [28] A culturally appropriate communication strategy may also address stigma. TB stigma was linked to HIV infection, another highly stigmatized infection as found in other studies [7] [29]. High rates of HIV infection in African settings may have contributed to this association. Education specifically about TB and HIV stigma from an African perspective may therefore help encourage TB health-seeking behavior [30].

The strengths of this study lies in the in-depth responses of the participants who identified their own solutions for overcoming barriers to TB health seeking behavior. It is limited by the small sample size; however, the responses were robust and allowed for theme saturation.

5. Conclusion

The lack of TB health seeking behavior among black Africans living in the UK can be explained by the HBM framework that provides the understanding of factors. This population holds mixed views and perceptions about tuberculosis and many barriers exist to current TB prevention efforts. Involvement of the non-UK-born black Africans communities in the TB prevention may be beneficial for reducing and tackling TB rates in this population. Such an approach is potentially inexpensive and more readily implementable than other suggested strategies, such as changes to immigration policies. Future studies should explore methods for engaging lay community workers in TB prevention, as well as their effect on TB screening rates. There is a need for more research about the factors which could affect the perceptions about TB among the UK-born Black Africans since this study only concentrates on the non-UK born black Africans.

Interviewer Guide

Good morning/afternoon, my name is Caroline Asiimwe and I am a student at Leeds Metropolitan University and I am here to conduct a study on the lay perceptions about Tuberculosis among non-UK-born black African

in Leeds, United Kingdom. First of all, I would like to register my appreciation for the valuable time that you will take to participate in this discussion. This study is aimed at exploring the lay perceptions about Tuberculosis among non-UK-born Black Africans. Therefore your views and opinions will help a great deal in the development of intervention strategies for TB prevention among the non-UK-born Black Africans in Leeds, UK.

Please be informed that there is no wrong or right answer during this interview, it is what you feel and say that matters and important to this study. This interview will last between 30 - 45 minutes and feel free to say exactly what you want to say.

Please be informed that the presence of my recorder is to record the interview and in this way will help me in the analysis and report writing so that no information mentioned during the interview is omitted. However, whatever you say here will be used for this research project and will not be shared to anyone outside the research team. To make sure that no one can identify you for the answers given your name will not be used. You have already consented to take part in this study using the consent form. Do you have any questions before we start the discussion?

Background information

No. of interview:

Age:

Gender:

Country of origin:

How long have you stayed in Leeds, UK, or tell me about yourself

Vignette:

Moses is a non-UK-born Black African who has lived in Leeds, UK for 3 years. He lives with his wife and a two-year-old daughter. His wife is unemployed and looking for work. Moses originally comes from sub-Saharan African where tuberculosis is most prevalent. Among many Black Africans, Moses lives in poor socio-economic conditions. However, Moses has a small part-time job that helps him pay his monthly bills, buy some food and look after his family. For quite some time, Moses has been feeling unwell with fever and cough. Moses decided to seek help from the medical practitioners in a nearby health unit. After several consultations and screening, Moses was told by the medical practitioner that he has tuberculosis.

Objective 1: Questions regarding perceptions of non-UK-born Black Africans about TB health risk.

1) What do you generally understand by tuberculosis?

Probe: cause, transmission.

2) So how did you obtain this information?

Probe: what could be other sources of information apart from the mentioned? So what did you hear?

3) How has this information over time?

Probe: compared to when you arrived in UK and now.

4) Studies show that the non-UK-born Black African is at high risk of acquiring TB. How do you perceive this in regard to TB risk?

Probe: why at high risk/why not at risk?

5) What could be the beliefs you consider important regarding the risk to TB?

Probe culture related.

6) In your opinion how would these beliefs influence you towards a particular action regarding TB?

Probe: seeking help, responding to information.

Objective 2: Questions related to seeking help in relation to TB.

1) What would motivate you to seek help if you are presented with symptoms of TB?

Probe: perceived threat to disease, cues to action (information, advice from health practitioners, campaigns, relatives, remainders), How?

2) What could be the problems to seeking help in relation to TB?

Probe: structural barriers-access to services, language, cultural barriers, personal barriers, stigma, social consequences, immigration status. How?

Objective 3: Questions about TB Health promotion opportunities.

Screening

1) What is your view on screening the non-UK-born Black Africans immigrants for TB?

Probe: in your opinion what makes it an improper to prevent TB? Why and how?

Probe: In your opinion what makes it a proper way to prevent TB? How?

2) What could be the problems associated with screening in relation to TB prevention and promoting health.
Probe: missed opportunities, tools for screening.
3) In your view what can be done better to improve screening to make it prevent TB and promote health. (Why and how?)

Health education

1) What is your view on the TB health education that is done in the UK?
Probe: effectiveness, reaching the minority (black Africans), reducing exposure, in terms of seeking help, reducing stigma, how?
2) In your opinion, what problems are related to TB health education provided?
Probe: language barrier, cultural barriers.
3) What can be done to make health education address TB among the non-UK-born Black Africans?
Probe effective way in getting information across the community (black African community) how?
Thank you for your time and contribution to this research.

Conflict of Interest

None of the authors has a potential conflict of interest.

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Appendix

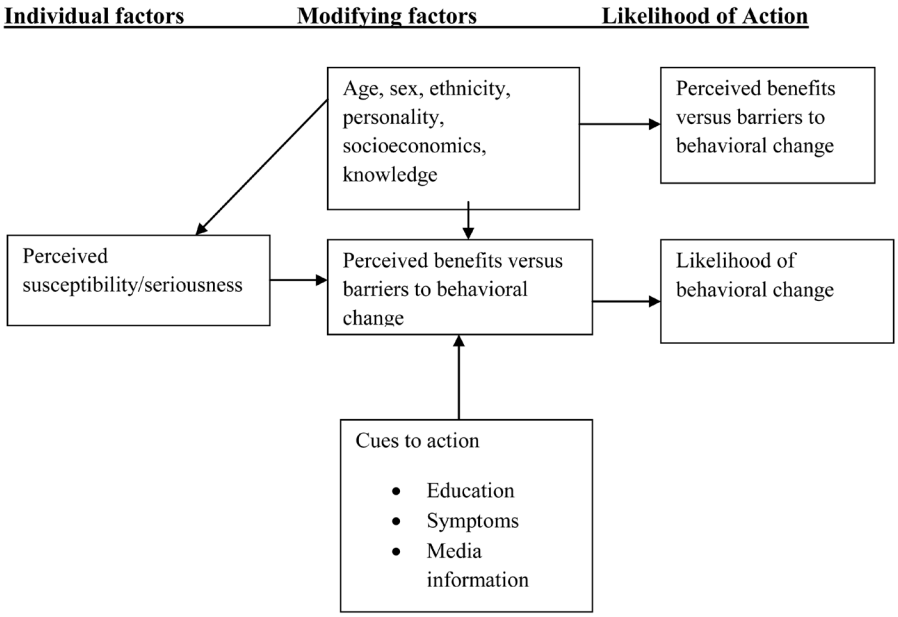

Figure 1. Health Belief Model.

Table 1. Socio-demographic characteristics of participants.

Age	Mean age	35.25
Marriage status	Single	4
	Married	7
	Cohabiting	1
Gender	Males	07
	Females	05
Education level	Secondary	2
	Tertiary/university	10
Duration of residence		1 - 5 years