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A disease called stigma: the experience of stigma among African men with TB diagnosis in London



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ABSTRACT

Objectives: Tuberculosis (TB) is a highly stigmatised disease. This paper sought to explore the experiences and meanings of stigma among African men with a previous TB diagnosis. **Study design:** Qualitative approach with ten men recruited from a community based organisation offering health support to the men.

Methods: In-depth semi-structured interviews.

Results: Men were unable to recognise TB symptoms and subsequently made late clinical presentation when they were also diagnosed with HIV. A few were diagnosed when in immigration detention centres. The experience of late diagnosis informed their understanding of the word stigma. The link between HIV and TB compounded experiences of stigma which led to depression and compromised HIV confidentiality.

Conclusion: TB late diagnosis among the men has implications for population health. Multidisciplinary teams supporting ongoing TB education programmes should include African men's organisations, due to the close supportive links such organisations have with African men.

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Introduction

Despite efforts to combat Tuberculosis (TB) through public hygiene, nutrition, TB medicines and better economic conditions, TB resurfaced as one of the greatest threats to public health in London resulting in the capital being dubbed the 'TB capital of Europe'.¹ TB is a barometer for health inequalities as a social gradient exists in the distribution of TB across London within deprived neighbourhoods with immigrants, accounting for three-quarters of all reported cases. Migration, poverty and poor living conditions amongst certain groups

have facilitated the spread of TB in European cities particularly amongst immigrants including black African men living in London.² Over the years, London has experienced increases and then declines in reported TB cases amongst black Africans, due to increasing numbers and changes within migration patterns amongst this population. In 2011, the majority of cases (85%) were found amongst people born outside the UK.² In 2014, rates of TB had fallen across different ethnic groups, including Africans and other migrants in London due to changes in migration patterns, pre-entry screening and an overall reduction in TB across the world.^{3,4} However, by the end of 2014, rates were 15 times

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higher amongst non-UK born people,⁴ particularly amongst men.³ In 2014, Africans were the third largest group (85 per 100,000) after Pakistan (96 per 100,000) and Indian ethnicity (123 per 100,000). Africans also accounted for one in five TB cases amongst people born in the UK.

TB is a highly stigmatised disease which, according to Goffman,⁵ is a 'social disgrace' depriving one of full social acceptance. Social acceptance is particularly important for some patriarchal cultures^{6,7} where valued masculinity places emphasis on 'strength' and income earning, influence men's willingness to access HIV services.^{8–10} In the UK, most studies on stigma and migrant populations have explored the experience of HIV stigma.^{11–13,9} HIV positive African migrant men in London found socio-economic contexts in which they lived their lives⁹ disempowering and affecting their engagement with public health interventions. A systematic review of qualitative evidence on TB and migration reports that the socio-economic and legal circumstances of migrants can have a detrimental effect on prognosis, diagnosis and treatment.¹⁴ A study in England found that participants were familiar with the characteristics and treatment of TB, but sufferers were said to likely experience felt and enacted stigma.¹⁵ Participants in a London clinic had misconceptions about TB and HIV was perceived as worsening TB stigma.¹⁶ Although studies have explored the experience of TB-stigma amongst men and women,^{17,16} little is known about the experiences of TB-stigma amongst African men in England and the implications for public health.

Entrenched in the debates about who gets TB is the concept of 'risk' with individual lifestyle placing certain people at higher risks. These risk factors include homelessness, drug and alcohol misuse, and imprisonment.¹⁸ The Office of National Statistics¹⁹ shows how black Africans in the UK are very socio-economically marginalised with African men having the highest proportion of unemployment. Black ethnic minority populations in Britain are overrepresented in the criminal justice system²⁰ and statistics from detention centres. The harsh socio-economic conditions experienced by some migrant African men such as unemployment/homelessness, problematise notions of 'ideal' masculine identity leading to feelings of failure.⁹ However, there is limited theorisation and conceptual models on how structural determinants intersect with stigma.²¹

The National Institute of Clinical Excellence (NICE)²² recommends a multipronged approach including vaccination, screening and educating the public and professionals about TB transmission and prevention. Most of these approaches focus on individual responsibility in averting risks, neglecting the wider determinants of health that shape the distribution of diseases across populations. NICE guidelines stress the importance of addressing TB-stigma. In this paper we focus on the experiences of stigma amongst ten African men with a previous TB diagnosis and how these experiences may impact on public health.

Methods

Participants were ten men who lived in London and self-identified as 'heterosexual African men' with a previous TB

diagnosis. Most defined themselves as 'married' fathers who lived separately from their wives and children. All the men had completed TB treatment. They were all born in different African countries including Zimbabwe ($N = 3$), Uganda ($N = 3$), Nigeria ($N = 2$), Ghana ($N = 1$) and Sudan ($N = 1$). Mostly ($N = 8$) were unemployed and a few ($N = 3$) had been in immigration detention centres. Their age ranged from 33 to 67 years old, all of them have been living in the UK for less than 15 years. They were interviewed in 2015.

The study received ethical approval granted by the University of Liverpool Ethics Committee. Participants were recruited through an organisation that offered health-related support to Africans in London. Although there were 200 African migrants recorded as having accessed services, due to funding cuts, the organisation was struggling to sustain its work and had lost contact with a number of the registered clients. Some had been dispersed or moved to outer London. It was also suggested that some registered service-users supported each other via social media, or met informally outside the organisation's premises. To protect the privacy of other members accessing services in this organisation, a member of staff distributed the information sheet to men who were visiting the organisation, inviting them to contact researchers if they wanted to take part in the study. This was a convenient sample. The inclusion criteria was that participants should identify themselves as African men who have recovered from TB, live in London and could speak English as there were no resources for translation services. It's less clear how many men were approached by the worker. Due to time constraints, we only interviewed 10 men who contacted the researchers. Interviews took place within the organisation's premises in a private room. This allowed the participants to better share their experiences in a confidential supportive setting. The consent form was signed before the interview took place. All participants received £10 to reimburse travel expenses.

Semi-structured interviews were conducted and lasted up to an hour and were led using a topic guide constructed using evidence from the literature and the study aims. Participants were asked about their lives, their understanding of the word 'stigma' and their experiences of living with TB. The men were also asked to explain how they got to know they had TB. Semi-structured interviews enabled the collection of data on a 'sensitive' topic, allowing participants to 'open up' and explain issues. The interviews were conducted by the second author who self-identifies as an 'African man'. All the interviews were audio-recorded and transcribed verbatim.

Analysis

The interview data was subjected to thematic analysis, using the interactive framework approach.²³ This involved familiarising ourselves with the transcripts and identifying meanings which were then grouped into themes and sub-themes. Initial themes were then coded to produce a coding matrix. In order to reduce potential bias, the authors discussed the themes for validation. Quotes are used to demonstrate key points. To maintain confidentiality, each participant is referred as 'P' with numbers 1–10 used to identify participants.

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