

Perceptions and experiences of tuberculosis among African patients attending a tuberculosis clinic in London

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SUMMARY

SETTING: Little is known of the social and cultural issues influencing the uptake of and attitudes to tuberculosis (TB) care by people of African extraction living in the UK.

OBJECTIVE: To describe the perceptions and experiences of African patients with TB in London, focusing on issues relating to diagnosis, treatment adherence and stigma.

DESIGN: Qualitative study using in-depth interviews.

RESULTS: Misinterpretation of early symptoms led to delays in seeking health care. Although half of the respondents reported denial of the diagnosis, they reported good treatment adherence, noting the role of TB specialist nurses in promoting adherence. Respondents felt stig-

matized by the diagnosis, although actual experiences of stigma were rare. Experience of TB in a known person mitigated stigma. Human immunodeficiency virus (HIV) disease was perceived to have worsened TB stigma, and most patients offered HIV testing initially declined, fearing stigmatisation and poor illness outcomes if positive. **CONCLUSIONS:** Awareness of TB can be improved among migrants at high risk of developing the disease and among health professionals. Counselling around HIV testing for TB patients must take their beliefs into account if a high uptake of testing is to be achieved.

KEY WORDS: tuberculosis; diagnosis; qualitative research; stigma

THE INCIDENCE OF TUBERCULOSIS (TB) is rising in the UK, particularly among migrants from regions of the world with high TB prevalence. The incidence in Black Africans is the highest, at 283 per 100 000 population, compared to 124/100 000 in those from the Indian subcontinent and 5/100 000 in the White UK population.¹ The importance of the association between TB and human immunodeficiency virus (HIV) infection has led to recommendations to promote HIV testing among individuals with newly diagnosed TB and vice versa.²

In certain communities in Africa, misconceptions about TB co-exist with deep fears about the disease.^{3–5} Both TB and HIV disease are associated with stigmatisation⁶ and, in these communities, similarities between symptoms of TB and HIV/acquired immune-deficiency syndrome (AIDS) have led to ‘cross-stigmatisation’ of TB and delays in treatment seeking in patients who also fear a diagnosis of HIV.

TB control in the UK combines voluntary presentation of symptomatic patients with active case finding by contact tracing and targeted screening.⁷ Early diagnosis and treatment is important to limit trans-

mission from infectious patients. The National TB Action Plan recommends that suspected cases of pulmonary tuberculosis (PTB) should be seen by the TB team within 2 weeks of first presentation to the health care services; however, this requires recognition of the possibility of TB.⁷ Upon diagnosis and commencement of treatment, close patient adherence to medication is vital to ensure cure and prevent the emergence of resistance. However, early presentation and patient adherence to treatment are complex behaviours that depend on symptom recognition and are influenced by social and cultural factors.⁸ Understanding how individuals experience or perceive their illness may shed light on factors affecting voluntary presentation and adherence, and improve the outcome of TB control efforts.

The advent of new entrant screening in the UK may mean that more cases of TB are detected in immigrants from high prevalence regions of the world. Properly planned and delivered care among these groups is key to good illness outcomes and wider protection of the health of the public.

We explored the experiences and perceptions of

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African-born people in London living with TB, focusing on issues influencing voluntary presentation and treatment adherence and experiences of stigmatisation.

METHODS

We consecutively enrolled eligible, consenting adults (aged ≥ 18 years) attending a clinic for TB treatment at the Homerton University Hospital in Hackney, East London, who were born in Africa, self-identified as African and were willing to be interviewed in English. As we were interested in the accounts of people who had been on treatment for active TB, we excluded individuals attending for preventive therapy as well as those attending the clinic to receive a diagnosis of TB for the first time. The sample size of 16 was determined by time constraints and non-emergence of new themes as the interviews progressed.

Potential respondents were invited to take part in an in-depth interview after their routine consultation. Those who agreed gave written informed consent. Interviews were conducted in a private room, using a semi-structured schedule of open-ended questions covering areas such as symptom onset, the treatment-seeking trajectory, disclosure, adherence and perceptions of the disease. Questions also explored experience of stigma, whether enacted (meaning actual experiences of stigma) or felt (meaning anticipated stigma). The domains covered were informed by Kleinman's explanatory model of patients' illness.⁹ This tool consists of eight questions to explore patients' perceptions and knowledge about their illness and includes domains such as aetiology, treatment and natural course of the illness. Answers were probed for additional detail. Each interview lasted 45–75 min, and was tape-recorded if permission was given. During transcription, para-linguistic features of the interview such as

pauses, emphasis and body language were noted. Interim analysis was pursued to expose emerging important themes and refine the extant questions. A grounded theory¹⁰ approach was used to analyse the data. This entailed coding the themes, topics and categories emerging from the transcribed interviews using the NVivo computer programme (QSR International, Doncaster, Victoria, Australia). These were then compared both within individual interviews and between interviews, revealing links between the data and common themes, thus leading to higher order generalisations. Important themes were explored further in subsequent interviews.

Ethical approval was granted by the Research Ethics committees of East London and City Health Authority and the London School of Hygiene & Tropical Medicine.

RESULTS

Eighteen patients receiving treatment for symptomatic TB were invited and 16 agreed to take part in the study. Of the two who declined, one insisted that she did not have TB (in spite of regular clinic attendance for care) and the other had recently participated in a similar study. The Table shows the demographic and clinical details of the 16 individuals who participated in the study. All participants had self-presented to health care services with symptomatic disease; none was identified by active case-finding programmes.

Misconceptions concerning TB

Misconceptions regarding the aetiology, transmission and outcome of TB were common. Various aetiologies were ascribed to TB, including heredity, poisoning and pneumonia. Some respondents believed that TB was acquired by sharing cutlery and having sex with sufferers. Respondents indicated that

Table Demographic and clinical details of respondents

Patient ID	Sex	Age, years	Country of birth	Years since entry into UK	Site of TB	Time since start of treatment, months	Time from symptom onset to diagnosis, weeks
1	M	39	Congo	14	Rib	8	17
2	M	31	Ghana	4	S+PTB	6	3
3	M	42	Ghana	3	S+PTB	1	3
4	M	19	Nigeria	3	S+PTB	2	10
5	M	45	Nigeria	20	LN	5	16
6	M	37	Nigeria	25	Miliary TB	4	3
7	M	44	Nigeria	22	S+PTB	4	5
8	M	31	Somalia	11	LN	9	7
9	M	28	Somalia	6	LN	7	3
10	M	29	Zambia	2	Miliary TB	5	4
11	F	25	Angola	23	S+PTB	5	2
12	F	38	Ivory Coast	10	Pulmonary LN	4	40
13	F	40	Nigeria	3	S+PTB	6	4
14	F	20	Somalia	4	LN	5	13
15	F	27	Somalia	3	LN	7	8
16	F	46	South Africa	6	S+PTB	4	5

TB = tuberculosis; M = male; F = female; S+PTB = sputum-positive pulmonary tuberculosis; LN = lymph nodes.

TB was a very severe illness and that it was highly transmissible.

[Talking about friend with TB] . . . we used the same utensils, shared the same toilet, bathroom, cups and glasses. And we weren't using disinfectants.

—37-year-old man, Nigeria

I thought. . . he passed it on to me through sex, like HIV.

—25-year-old woman, Angola

Despite misconceptions, the respondents were clear that TB that did not affect the lungs was not transmissible. Health providers were reported to make the distinction between infectious and non-infectious TB early to the patients, presumably as part of infection control measures.

Symptom misinterpretation

Most individuals misinterpreted their initial symptoms of TB, attributing them to the flu, food poisoning, boils or strenuous activity, resulting in delays in seeking advice from a health professional:

It started as a lump which grew bigger and bigger. I first thought it was a boil. I left it like that for about three months during which it kept getting bigger.

—20-year-old woman, Somalia

I suspect it must have been food poisoning. I think it must have contributed to the illness or triggered it.

—37-year-old man, Nigeria

I thought it was because of the heavy load I carried. I did not report the chest pain for about three weeks. When I coughed and saw blood, then I came to the doctor.

—31-year-old man, Ghana

Some respondents also reported that health care providers failed to consider TB early in the course of their illness, resulting in delays in arranging appropriate investigations and onward referral:

I was coughing and I went to the GP and he said it was a virus that will go after some weeks. I went back later and he said the same thing.

—45-year-old man, Nigeria

I started coughing in November and it wasn't until mid January that I was referred to hospital for chest X-ray.

—19-year-old man, Nigeria

I had chest pain . . . I was brought to the emergency . . . the doctor examined me and gave me a painkiller. As I was about to leave, I coughed and, it was all blood.

—40-year-old woman, Nigeria

Denial of the diagnosis

Nine of the 16 respondents did not believe that they had TB. Respondents who did not accept the diagnosis often had misconceptions about the nature of their illness, had experienced longer times to diagnosis and

initial uncertainty of the diagnosis, and had no prior experience of TB in a known or close person:

I didn't believe it, to be honest . . . there's nothing relating to TB in my family. If you have this thing [TB] in your family, then it may come to you, so me, I don't believe it.

—31-year-old man, Ghana

I am not convinced it is TB I have. First, they say it is this illness [sarcoidosis], then they say it is TB.

—38-year-old woman, Ivory Coast

I said 'no I haven't got TB'. I used to hear about it but I never knew it might come close to me . . . but you know until you know someone who has it, you do not feel it near you like that.

—19-year-old man, Nigeria

Those who had had experience of TB reported differently:

[The diagnosis] was no problem because we know it. My cousin, everyone, they have TB before. So when I told them, look I have got TB, they said no problem.

—20-year-old woman, Somalia

Despite denial, however, respondents reported good adherence to medication. Factors reported to facilitate adherence included counselling by health care staff, personalised care from TB specialist nurses and advice from well-informed social contacts. Difficulties with the large quantity of pills and perceived side effects of medications, such as general physical weakness, were reported as challenges to adherence.

Contexts of stigma

Actual experiences of stigmatisation (enacted stigma) were reported mainly by those who had been source-isolated in a hospital ward in accordance with infection control policy.

I felt bad. I mean I am not an alien. You see all those nurses all masked up. It wasn't a good feeling. People treating you differently, you're separated from all others [hisses]. It was hard.

—19-year-old man, Nigeria

Among others, actual stigmatisation was uncommon. Where experienced, it related to poor knowledge about TB and the belief that it was easily transmissible and grave in outcome:

My nephew, who used to come and see me, when he heard that I had TB, started staying away. He thought that if he came close to me, he will contract it and will start dying.

—40-year-old woman, Nigeria

More commonly, felt stigma was reported. In anticipation of stigma, some respondents restricted their social circles to limit the possibility of stigmatisation:

After they told me, I came home and said there are some things I use and nobody should use it. I kept my own cup, my own spoon . . .

—39-year-old man, Congo

HIV 'cross-stigmatisation' of TB

Some respondents said that the association of symptoms such as weight loss and cough with HIV infection had led to increased stigmatisation of TB:

It is always like 'He's got TB; he must be HIV positive'. That's the way people look at it. I think people see that the symptoms look alike, so they just conclude that anyone with TB has HIV.

—29-year-old man, Zambia

One respondent reported that this suspicion was evident in the way a member of medical staff (a doctor of African origin) questioned her about her symptoms:

He asked about TB, AIDS and sex. You could tell from the way he was asking the questions that he was suspecting I had AIDS. I wasn't happy at all. He just told me to do an AIDS test and moved on.

—46-year-old woman, South Africa

Most respondents who were offered HIV testing in the course of treatment initially declined because they were worried about the outcome and the possibility of stigmatisation.

I requested not to do it [HIV test]. I wasn't sure. I thought to myself, if I get that news, I would die.

—46-year-old woman, South Africa

These days, if you have TB, they say it's AIDS. If you have pneumonia, they say it's AIDS. If you have common fever, make sure you stay inside your house! Once you lose one kilogram, you're finished. Some won't even shake your hands or eat with you. The stigma is too much. So people prefer to die.

—37-year-old man, Nigeria

DISCUSSION

This study employed in-depth interviews to explore the experiences of Africans with TB in the UK. Although similar studies have been conducted in low-income settings, this approach has not, to our knowledge, previously been used to explore how stigma and TB-related perceptions shape uptake and attitudes to TB care in a high-income country setting.

In some respondents, symptom misinterpretation appeared to contribute to delayed treatment seeking and longer times to diagnosis. Symptom misinterpretation is not surprising if we consider that early symptoms of TB are non-specific and may be attributed to self-limiting illnesses, such as viral infections. Some delay in seeking medical advice might thus have been inevitable. Appreciation of low-grade fever ($<38^{\circ}\text{C}$) in Africans is uncommon.¹¹ The symptoms may have been interpreted as influenza, in which case widely publicised advice recommends not visiting the doctor. Individuals with unexplained weight loss may fear a diagnosis such as cancer or HIV infection and thus delay seeking medical attention. Although the risk that a patient with TB also has HIV infection is lower

in the UK than in many African countries, migrants from settings where HIV prevalence is high may share such concerns.

The study also illustrates how some participants respond to the diagnosis of TB by retreating into denial. The firm response of a 19-year-old man ('No, I haven't got TB') to the diagnosis of TB aptly captures the denial observed in over half of the respondents. Denial in our respondents appeared to be attributed to initial uncertainty about the diagnosis and a sense of felt stigma. However, even those patients who were in denial reported good adherence, an outcome attributed to the role of the TB specialist nurses. Although it is the experience of some experts¹² that denial is an immediate response that fades away with time, giving way to more active coping strategies, in our study even respondents who were nearing the end of treatment expressed denial, a sense of isolation, enacted by not sharing meals, cutlery and avoiding sexual intercourse. There were few experiences of enacted stigma, although a sense of shame was reported. A sense of stigma was less often reported in those who had been on treatment longer.

One limitation of this study is its size. Moreover, the respondents studied are not a representative sample either of TB patients or of Africans with TB in the UK. We cannot therefore be sure that the views reported here can be generalised to other TB patients.

Good treatment adherence despite apparent denial of the diagnosis highlights the modifying role of extrinsic factors on patients' experiences of TB care. Those reported factors reinforcing adherence included informed social networks and more personal care from health staff. Treatment might thus be more successful if there is trust between the individual and the TB team.

Stigma related to HIV infection may reduce HIV test uptake in TB patients. Counselling around HIV testing in TB care must therefore take into account patients' beliefs and concerns about felt stigma. In line with this, 'expert patients' who have had good outcomes of TB treatment may prove helpful in dissipating stigma, promoting early diagnosis and improving case holding amongst migrant populations.

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R É S U M É

CONTEXTE : On ne sait que peu au sujet des problèmes sociaux et culturels qui influencent la compréhension et les attitudes à l'égard des soins pour la tuberculose (TB) chez des personnes d'origine africaine vivant au Royaume Uni.

OBJECTIF : Décrire les perceptions et les expériences des patients africains en matière de TB à Londres, en se concentrant sur les problèmes en rapport avec le diagnostic, l'adhésion thérapeutique et la stigmatisation.

SCHEMA : Etude qualitative utilisant les interviews approfondies.

RÉSULTATS : Une mauvaise interprétation des symptômes précoces a entraîné des délais dans le recours aux soins de santé. Bien que la moitié des répondeurs aient signalé un déni de diagnostic, ils ont également signalé une bonne adhésion thérapeutique en notant le rôle joué par les infirmières spécialistes en TB à la promotion de cette

adhésion. Les répondeurs se sont perçus comme stigmatisés par le diagnostic alors que les expériences effectives de stigmatisation étaient rares. L'expérience de la TB chez une personne connue a mitigé la stigmatisation. La maladie due au virus de l'immunodéficience humaine (VIH) est perçue comme ayant aggravée la stigmatisation de la TB et la plupart des patients à qui on offre un test VIH l'ont refusé initialement par crainte de la stigmatisation et des médiocres résultats de la maladie en cas de positivité.

CONCLUSION : La prise de conscience de la TB peut être améliorée chez les immigrants à risque élevé de développement de la maladie ainsi que chez les professionnels de la santé. L'accompagnement entourant le test VIH pour les patients tuberculeux doit prendre en compte leurs croyances si l'on veut arriver à une bonne compréhension du test.

R E S U M E N

MARCO DE REFERENCIA : Poco se conoce sobre los aspectos sociales y culturales que determinan la búsqueda de atención y la adherencia al tratamiento de la tuberculosis (TB) en las personas de origen africano que viven en el Reino Unido.

OBJETIVO : Describir las percepciones y experiencias de los pacientes africanos con TB en Londres, con especial interés en aspectos relacionados con el diagnóstico, el cumplimiento terapéutico y la estigmatización.

MÉTODOS : Estudio cualitativo mediante entrevistas en profundidad.

RESULTADOS : La interpretación errada de los síntomas iniciales condujo a un retraso en la búsqueda de atención de salud. Si bien la mitad de quienes respondieron refirieron una negación del diagnóstico, también comunicaron un buen cumplimiento terapéutico, destacando la función de promoción de la adherencia al tratamiento por parte del personal de enfermería especializado en

TB. Los encuestados se sintieron estigmatizados por el diagnóstico, aunque las experiencias reales de estigmatización fueron escasas. La experiencia de la TB en una persona conocida mitigó el estigma. La presencia de infección por el virus de la inmunodeficiencia humana (VIH) se percibió como agravante del estigma de la TB y la mayoría de pacientes a quienes se ofreció la serología diagnóstica la rechazaron inicialmente, temiendo la estigmatización y un desenlace terapéutico desfavorable en caso de positividad.

CONCLUSIONES : Es posible mejorar el conocimiento sobre la TB en los inmigrantes con alto riesgo de TB y en los profesionales de la salud. Durante la orientación a la prueba para el VIH en los pacientes con TB deben entrar en consideración las creencias de la población, si se espera conseguir un alto porcentaje de aceptación de la prueba diagnóstica.