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The social context of tuberculosis treatment in urban risk groups in the United Kingdom: a qualitative interview study



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SUMMARY

Objectives: There is scant qualitative research into the experiences of tuberculosis (TB) treatment in urban risk groups with complex health and social needs in the UK. This study aimed to describe the social context of adherence to treatment in marginalized groups attending a major TB centre in London.

Methods: A qualitative cross-sectional study was performed using semi-structured interviews with patients receiving treatment for TB. Analytical frameworks aimed to reflect the role of broader social structures in shaping individual health actions.

Results: There were 17 participants; the majority were homeless and had complex medical and social needs, including drug and alcohol use or immigration problems affecting entitlement to social welfare. Participants rarely actively chose not to take their medication, but described a number of social and institutional barriers to adherence and their need for practical support. Many struggled with the physical aspects of taking medication and the side effects. Participants receiving directly observed therapy (DOT) reported both positive and negative experiences, reflecting the type of DOT provider and culture of the organization.

Conclusions: There is a need for integrated care across drug, alcohol, HIV, and homeless services in order to address the complex clinical co-morbidities and social needs that impact on the patient's ability to sustain a course of treatment.

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1. Introduction

A recent cross-sectional survey of tuberculosis (TB) notification rates across the European Union (EU) reported that 15 out of 54 cities had notification rates twice the national country rate, with some cities experiencing rates three to four times the national level.¹ These included Birmingham and London (UK), Brussels (Belgium), and Rotterdam (Netherlands). The authors attributed the high rates of TB in major conurbations, in countries otherwise classified as having a low incidence of disease, to the high concentration of urban risk groups. This raises particular challenges for a national TB control programme.

Cases of TB are over-represented in socially and economically marginalized groups in high-income countries. In 2013 in the UK, for example, 70% of the TB caseload came from the 40% most deprived areas, and 44% of TB cases did not have employment.² Groups that are affected by TB in the UK include migrants from high TB endemic countries, homeless populations, prisoners, people living with HIV/AIDS (PLWHA), and people who use drugs (PWUD) and alcohol. These groups are at greater risk of TB than the general population. They also comprise 38% of non-treatment adherent cases, 44% of cases lost to follow-up, and 30% of cases deemed highly infectious, and represent approximately 17% of the London TB caseload.³ Approximately 10% of the national caseload is characterized by at least one social risk factor associated with non-adherence, including drug abuse, alcohol abuse, homelessness, and imprisonment (3.2%, 3.9%, 3.3%, and 2.9%, respectively).² Failure to adhere to a prescribed course of treatment can result in the development of drug-resistant disease (which is more difficult

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and expensive to treat), serious morbidity and mortality, and an increased risk of transmission.⁴

The World Health Organization (WHO) has endorsed the use of supervised pill-taking (directly observed therapy, DOT) as the standard of care to promote adherence, although this has not been applied consistently in the UK context,³ with fewer than half of eligible patients receiving DOT in 2013.² This can either be interpreted as a failure of services to upscale DOT, or that some patients are perceived to be able to manage a course of treatment without DOT.

Two reasons for non-adherence to medication have been theorized: unintentional non-adherence (people intend to take medication but fail to do so in the correct way), and intentional non-adherence (people choose not to take medication).⁵ Criticism of the adherence literature has been the dominance of psychological approaches, which over-emphasize individual agency, particularly in marginalized populations where choice and control are most constrained.^{6,7}

Gaining a better understanding of how wider contextual factors impact on adherence is crucial if we aim to develop responsive services that address both clinical and social needs. For example, the results of two systematic, qualitative reviews concluded that adherence to TB treatment was dependent on a range of complex and interrelated factors, including both personal and structural factors, the configuration of health services, and the social and economic context.^{8,9} The WHO adherence framework additionally emphasizes therapy and condition-related factors (e.g., side effects and co-morbidities).¹⁰

In this study we aimed to contextualize the experiences of our participants within a 'social determinants of health' framework^{11,12} in order to highlight how broader social structures shape individual health actions that give rise to intentional and unintentional non-adherence. We also aimed to identify examples of 'resilience strategies' that our participants adopted to manage their treatment.⁵ The study formed part of a wider service development project conducted in London, UK, which aimed to develop a social outreach model of care for marginalized groups with TB and generate an evidence base for the need of a TB caseworker in supporting clients with complex needs; this project is reported elsewhere.^{13,14}

2. Methods

2.1. Recruitment

Participants in this interview study were recruited from a major TB centre characterized by a culturally diverse catchment area including migrant and homeless populations, between 2003 and 2004. Interviewees were selected for inclusion based on a risk assessment¹⁴ completed by nurses; this identified factors that could complicate adherence to treatment (e.g., drug use, homelessness, and missed appointments) and the need for referral to a caseworker for enhanced case management. Participants were referred to the researcher by nurses or a case worker at different stages of their treatment. Sampling was broadly purposive and reflected a range of 'critical case' experiences typical of those presenting with complex needs and the caseworker's caseload.^{15,16} Participants were informed that the study was part of a new initiative developing a social outreach model of support.¹⁷ Interviews lasted between 30 and 60 min and covered broad-based themes about experiences of treatment. The majority of interviews took place in the hospital outpatient clinic; three took place on a hospital ward, one took place in a homeless hostel, and one in a prison with the permission of managers. Clinic interpreters were used in two cases. Interviews generally coincided with patient appointments and they were offered a food voucher to the

value of £5. Due to the difficulty of researching this group within a clinical environment (e.g., lack of private spaces, frequent interruptions) and because some patients experienced different social risks impacting on adherence later in their treatment (e.g., people became homeless or their immigration status changed affecting entitlements), participants were interviewed on more than one occasion. All interviews were audio recorded and transcribed verbatim, except for the two interviews involving interpreters and one in the prison. Here notes were taken.

2.2. Analysis

The analysis was informed by a critical health psychology perspective that understands illness behaviour within social, political, and cultural contexts, which not only influence health and illness, but healthcare organization and delivery.¹⁸ We adopted a theoretical thematic analysis¹⁹ involving both deductive (top down) and inductive (bottom up) coding and linking codes, drawing on the WHO adherence framework (i.e., personal factors such as resilience, social and economic contexts, therapy- and condition-related factors, and healthcare systems). Segments of relevant text relating to adherence and contextual information were identified and compared across transcripts. Analytic memos were used to aid analysis. Data analysis was managed using a computer software programme designed specifically for the coding and retrieval of qualitative data (QSR NUDIST*Vivo 10). Coding was compared and corroborated between researchers, one with a social science background and one with a background in nursing and homelessness.

2.3. Ethical considerations and consent

This research was carried out within the guidelines of the University College London Hospital Research Ethics Committee, which approved the study. Written or verbal consent was obtained (as agreed with the Ethics Committee). Participants were advised that the interview did not form part of their clinical care. If the participant became tired or agitated, the interview was terminated and rescheduled. Where a participant became distressed or disclosed distressing experiences, the researcher terminated the interview and offered a referral to the caseworker.

3. Results and discussion

3.1. Participant characteristics and the wider context of adherence

Seventeen participants were interviewed: 16 with a confirmed diagnosis of TB and one with suspected TB. The majority of interviewees were male (71%; 12/17). Just over half were born in the UK (59%; 9/17); six of these participants described their ethnicity as White British. The remainder were of Irish origin ($n = 2$), Black British ($n = 1$), or Black African ($n = 2$); one woman described herself as Jewish. Of those born outside the UK, two were Ethiopian and three were Somali. The mean age of respondents was 44 years (range 18–67 years; $n = 16$) at the start of their initial treatment. [Table 1](#) provides further details, including co-morbidities and drug resistance.

3.2. Income, housing, and employment

The majority of participants were homeless according to statutory legislation. Five participants had complex immigration cases affecting their entitlement to housing and welfare. Three became unemployed due to illness and were therefore left without an income. The remainder were in receipt of social welfare or a voucher scheme (used in exchange for food in designated shops).

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