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Article for IJID special issue: World TB Day

Title:

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

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Abstract

Objectives There is scant qualitative research into the experiences of tuberculosis 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 marginalised groups attending a major tuberculosis centre in London.

Methods Qualitative cross-sectional study using semi-structured interviews with patients receiving treatment for tuberculosis. Analytical frameworks aimed to reflect the role of broader social structures in shaping individual health actions.

Results Seventeen 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 DOT reported both positive and negative experiences reflecting type of DOT provider and culture of the organisation.

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

Keywords: Tuberculosis, social determinants, adherence, homeless persons, drug users, stigma

Background

A recent cross-sectional survey of tuberculosis notification rates across the European Union (EU) reported that 15/54 cities had notification rates twice the national country rate with some cities experiencing rates 3-4 times the national level.¹ These included: Birmingham and London (UK), Brussels (Belgium) and Rotterdam (the Netherlands). The authors attributed high rates of tuberculosis 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 marginalised 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, 30% of cases deemed highly infectious and represent approximately 17% of the London TB caseload.³ Approximately 10% of the national caseload is characterised by at least one social risk factor associated with non-adherence including drug or alcohol abuse, homelessness and imprisonment (3.2%; 3.9%; 3.3%; 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 and expensive to treat, serious morbidity and mortality and increased risk of transmission.⁴

The World Health Organisation (WHO) has endorsed the use of supervised pill taking (DOT) as the standard of care to promote adherence although this has not been consistently applied in the UK context³ 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 theorised: unintentional non-adherence (people intend to take medication but fail to do so in the correct way) or intentional non-adherence (people choose not to take medication).⁵ Criticism of the adherence literature has been the dominance of psychological approaches which over-emphasise individual

agency, particularly in marginalised 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 which address both clinical and social need. For example, the results of two systematic, qualitative reviews concluded that adherence to tuberculosis 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 emphasises therapy and condition related factors (e.g. side effects and co-morbidities).¹⁰

In this study we aimed to contextualise the experiences of our participants within a social determinants of health framework^{11,12} to highlight how broader social structures shape individual health actions which 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 marginalised groups with TB and generate an evidence base for the need of a TB caseworker in supporting clients with complex needs and is reported elsewhere.^{13,14}

Methods

Recruitment: Participants in the interview study were recruited from a major TB centre characterised by a culturally diverse catchment area including migrant and homeless populations between 2003 and 2004. Interviewees were selected for inclusion based on a risk assessment,¹⁴ completed by nurses, which identified those factors which could complicate adherence to treatment (e.g. drug use, homelessness, missed appointments) and the need for a referral to a caseworker for enhanced case management. Participants were referred to the researcher by nurses or 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 minutes and covered broad based themes about experiences of treatment. The majority of interviews took place in the hospital outpatients’ clinic, three took place on a hospital ward, one interview 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 patients' 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.

Analysis

The analysis was informed by a critical health psychology perspective which understands illness behaviour within social, political and cultural contexts which not only influence health and illness, but health care organisation 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 (ie. personal factors such as resilience, social and economic contexts, therapy and condition related factors and health care 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.

Ethical considerations and consent: This research was carried out within the guidelines of University College London Hospital's 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 interviews were terminated and rescheduled. Where participants became distressed or disclosed distressing experiences, the researcher terminated the interview and offered a referral to the caseworker.

Results and discussion

Participant characteristics and the wider context of adherence

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

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 voucher scheme (used in exchange for food in designated shops). Participants described a range of measures to supplement their income including: sex work, begging, stealing to obtain food or drugs, reliance on food handouts, informal assistance from relatives, casual labour and community support.

Drug and alcohol use

Nine (53%) participants reported drug use including polydrug use. Seven participants were receiving opioid substitution therapy (OST, methadone maintenance) at the time of interview. PWUD also reported consuming alcohol, but to different degrees. Three other participants reported problematic alcohol use. Everyday routines were dominated by drug and alcohol consumption and for people who injected drugs (PWID), measures to finance their drug use and prevent drug withdrawal syndrome.

Experiences of violence and social exclusion

Many participants disclosed past experiences of violence, torture, physical and sexual abuse. Others spoke of lives dominated by a cycle of crime, including youth offending, drug use and imprisonment. Their experiences were firmly embedded within narratives of violence and exclusion²⁰ and, in some cases, illustrated the cumulative effect of disadvantage impacting and constraining behavioural choices.^{10,11}

Support

Lack of social support from friends and family was a significant issue for many participants due to their migrant/refugee status or because they were estranged from their family. Few were able to identify people who offered support on a regular basis. Some family members were reported to provide financial support, but not emotional or practical aid. People who were homeless mostly had other homeless people in their social network that limited the type of support available. One person reported increased support from his family following a noticeable improvement in his condition (ID12). Another received support from a close friend who would ring him to remind him to take his medication (ID03). In general the participants were reliant on the TB clinic for support or hostel workers who would remind patients to take their medicines or accompany them to clinic appointments. However this was not always consistent as funding sources, and lack of training, often precluded assistance with health care. One man reported that hostel staff would not come to his room if he was too ill to get up:

They don't [check on you]. No. Because they say they are, it is not a nursing home (ID04)

When asked about the type of support needed, participants responded with reference to material or practical assistance such as finding a job, housing, money to buy 'good' food, assistance with shopping, coming off drugs and, someone to talk to.

Disclosure and stigma

An older Somali refugee described how she hid her diagnosis and her TB medication from the relatives she lived with, administering them in secret. Her fear of disclosure related to the threat of eviction and rejection by the wider Somali community resulting in a loss of material and social support:

I keep medication in a secret place and take medication at a secret time. The other illness (diabetes) they (relatives) know about it and accept it. The first thing I will lose is my accommodation and the relationship. My situation could then be communicated to other Somalians (ID07)

Scambler²¹ suggests the fear of negative reactions (felt stigma) can be more detrimental psychologically than the actual experience of discrimination (enacted stigma) because of the effort people expend when trying to conceal their condition. According to this theory people

become so adept at concealment as a first choice strategy that examples of enacted stigma are rare. Moreover the adverse effects of stigma may have a greater impact on women because of their (gendered) social location.²² Some participants reported that the disease was used as an excuse to shun or evict a person because of dislike (ID03) rather than stigma. Others noted social distancing (ID01), sympathy (ID05), indifference (ID02) and acceptance where family were able to witness the beneficial effects of treatment (ID12).

Health Care Systems

Hospital practice on methadone maintenance, drugs and alcohol consumption

Although there are guidelines on OST to stabilise PWID while in hospital²³ there was a perception that, along with other drugs obtained illicitly (eg.valium/diazepam), these were under-prescribed. The frequency of dosing, sometimes with long intervals due to delays in administering methadone, was such that some patients experienced withdrawal syndrome.²⁴ This was frightening where they felt they had little control illustrating the psychosocial aspects of withdrawal. Physicians may fear the consequences of over-prescribing methadone and the conflicts experienced between meeting the needs of patients and adhering to prescribing protocols, with the potential for impact on the therapeutic relationship, has been documented.²⁵

As some hospital wards operated a zero tolerance policy in relation to drug and alcohol use participants reported leaving the hospital to obtain drugs to cope. Some reported that staff, adopting a lenient approach, turned a blind eye to alcohol use off premises providing patients returned to the ward; a ‘compromise’ to encourage adherence to treatment plans. Consultants sometimes refused to treat patients unless they agreed to modify their behaviour. In extreme cases patients were coerced into complying with treatment in order to avoid compulsory detention.

Hospitalisation as a safety net or welcome break

In contrast to those who experienced drug withdrawal while in hospital, one homeless man was more able to tolerate the demands of hospitalisation which he viewed as a welcome break from the cold and months of homelessness living on the street: ‘it was like a bit of a holiday’ (ID05). As a methadone user with occasional heroin use, his daily routines were less dominated by drug use and withdrawal.

In some cases, interviewees experienced lengthy periods of hospitalisation for social reasons in addition to medical need. One young woman spent several months in hospital due to homelessness and a history of sexual exploitation (ID10). Despite having lived in the UK since a child, her immigration status precluded any recourse to public funds rendering her destitute. The doctors decided to delay discharge from the hospital because she was very young and vulnerable. She remained an in-patient for several months until the Social Services accepted they had a duty of care and provided accommodation allowing a safe-discharge and stable environment for her to complete her treatment.

Directly Observed Therapy (DOT)

Those patients receiving medicines through DOT (n=9) spoke of the benefits in terms of contact with ‘normal people’ and ‘female company’ (for some homeless men), support from staff and the structure the clinic visits afforded: ‘the day I’m not going to the clinic it’s difficult to get up. It’s my day out’ (ID01).

For PWID DOT was provided at a number of locations including: the Drug Dependency Unit (DDU) or pharmacist in conjunction with methadone, the hostel via outreach workers or, the TB clinic. However DOT was not always successful even where the location or provider changed. PWID did not always attend the DDU, either because of the distance they had to travel, or because they had used or intended to obtain drugs. The monitoring of pill swallowing also varied across different healthcare locations; whereas some staff made distinct efforts to check that all pills had been swallowed, particularly where methadone was dispensed, others supervised at arm’s length “out of the corner of their eye”. There was however evidence of resentment where DOT was administered in an authoritarian atmosphere:

I hated it. Um, (pause) I felt that, I was threatened, you know, it's like, if you didn't take this, then you couldn't have that I felt like I was at school. And, in the end I just wanted to say: **** the lot of you. Because I couldn't take the TB pills you know, my body did not want the pills any more, but, my body still needed the methadone. (ID15)

Personal Factors

Experience of medication and resilience strategies

For those participants not receiving DOT, a dominant theme was the way treatment regimens impacted on everyday routines, compounded by the number and size of tablets and frequency of dosing.²⁶ A health care worker taking medication for both HIV and TB spoke of the day dominated by pills and the difficulty of taking the prescribed regimen when trying to maintain daily routines such as shopping. She took nine pills in the morning, seven at lunch time, three in the afternoon and seven at night. The only way to manage her regimen was to skip the afternoon dose:

I've never missed my morning, drugs and my night drugs. But my afternoon drugs: yes.
(ID08)

This example illustrates the limitations of pill organisers when faced with the demands of the schedule of dosing. It wasn't her memory that failed her; rather, the lack of practical support with her daily activities. Others appeared more able to incorporate tablets into their daily routines where pill taking already formed part of their everyday lives (e.g. pills for hypertension).

The difficulty of combining medication with an itinerant lifestyle and the storage of medicines was a major problem. One homeless man had his bag stolen (ID05) and others reported difficulties carrying medicines with them such that where they had stored their medication was not where they ended up sleeping. Participants reported running out of medicines. The requirement to take medicines on an empty stomach, one hour before food, when some patients had little control over the availability of food in terms of supply or affordability was also a factor, particularly where they depended on 'handouts' provided by charities. Here food was prioritised over pill taking. Others radically changed their eating and sleeping patterns in order to take medication.²⁷ One participant ensured that she didn't eat anything after 3am in order to take her morning medication on an empty stomach. Another reported that he missed his medicines if looking for money to buy drugs or if taking heroin instead of methadone.

Those with more routinised and stable lifestyles were able to manage their medicines and devised resilience strategies by creating reminders⁵ such as setting an alarm clock, or memory aid, in the form of a chart, to record pill taking. Others attempted to cut up or crush tablets

(although not medically recommended) or consume with nutrient drinks to avoid feeling sick. Modifying regimens rather than take medicines as prescribed has been described as ‘purposeful non-adherence.’²⁷

The quality of reminder cues also varied and some were more vulnerable to failure as in the example of the homeless man who struggled to take his medication due to a combination of poor memory, tiredness, problems swallowing and alcohol use (ID02). He developed a routine which involved leaving his tablets in a place near to where he slept only to awake to find someone had moved them.

Therapy related factors and co-morbidities

Adverse effects of medicines

Although much emphasis is placed on adherence to treatment, the adverse effects of therapy receive less attention.²⁷ Some reported feeling nauseas or vomiting following their medicines (‘Most day I vomit after taking my medication’ (ID08)) which may have been due to the number of tablets, particularly where administered through thrice weekly DOT (ID14). Numbness and dizziness (D08) has also been reported in patients taking antiretrovirals.²⁷ Others described what appeared to be adverse drug reactions which caused them to interrupt their treatment. The side effects of isoniazid also include nausea, vomiting and numbness. Some PWUD found it difficult to distinguish between the symptoms of tuberculosis, other co-morbidities and the adverse effects of medication:

Feel better but can't remember feeling bad because so wrapped up in drugs and alcohol. Walking from the hostel to get methadone, I was sweating like mad. Can't remember if it was TB drugs, drink or combination. (ID01)

Conversely another patient was able to attribute the cause of his symptoms specifically to TB medication because of withdrawal syndrome, reflecting the way rifampin reduces the effect of methadone.²⁸

The tablet's, actually, [have] halved, the dosage of methadone. So instead of me being on a hundred and twenty five, I'm only getting sixty two and a half per cent in my body, because the pills are wiping out, the other sixty two and a half per cent. (ID14)

His methadone was later increased to compensate. Alcohol consumption resulting in vomiting, diarrhoea or blackouts was also given as a reason for not taking medicines (ID16).

Conclusions

Research has theorised two reasons for non-adherence: intentional and non-intentional. The results of this study has highlighted the structural and institutional contexts impacting on adherence to treatment.²⁹ Drug and alcohol use was clearly a complicating factor as was homelessness but other factors included: the culture of services (e.g. perceived to be authoritarian or punitive); institutional policies (e.g. methadone prescribing practices and zero tolerance on drug and alcohol consumption resulting in withdrawal syndrome, patients leaving the hospital); lack of effective partnership working with homeless organisations or financial restrictions placed on those organisations by funders impacting on their ability to support patients); requirements to take medication in prescribed ways geared toward those with routinised lifestyles (e.g. in relation to mealtimes) or the adverse effects of therapy coupled with complex co-morbidities (resulting in nausea and vomiting). Those receiving DOT reported both positive and negative experiences relating to type of DOT provider and culture of the organisation.

Participants appeared more able to sustain a course of treatment where their environment was stable and where they received support through friends, family community services or case worker which played an important role. Practical support was valued and has been found to support adherence in other conditions.³⁰ Some participants showed evidence of quite sophisticated resilience strategies in managing their medication.

A Cochrane review of research to promote adherence more generally³¹ identified 21 strategies which, with little exception (e.g. group meetings), focused on interventions at the individual patient level. In our study however, people rarely actively ‘chose’ not to take their medication. Rather adherence to treatment involved a complex interplay of factors involving their social location, co-morbidities and service policy and delivery. Interventions that target individual coping skills therefore are unlikely to meet with success in marginalised populations, such as those described here, in the absence of measures which address the ‘risk environments’³² (e.g. homelessness) which render people vulnerable to both TB disease and non-adherence to treatment.

Rather than view non-adherence as individual failure, a more productive approach would be for services to collectively share the responsibility for treatment adherence, and any associated risks, through the co-creation of localised, inter-sectoral, collaborative care pathways which integrate drug, alcohol and homeless services and which are able to address

both clinical and social risks.^{17,33} This will require smarter approaches to commissioning joint health and social care services with implications for resourcing and workforce development.

Conflict of Interest Statement:

None declared

Author Declaration

GC was the lead researcher and interviewed participants, analysed data, developed analytical frameworks and drafted the manuscript. She had no involvement in the clinical care of patients.

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This research was carried out within the guidelines of University College London Hospital's Research Ethics Committee which approved the study.

Table 1 Social characteristics of interviewees

Int ID	Usual pattern of housing+	Place of birth	Criminal justice	Drug use	OST	Alcohol	HIV+	Other self reported health conditions	Drug resistant TB
ID01	Hostel	UK	✓	PWID	✓	✓		Epilepsy	INH
ID02	NFA	UK	✓			✓		Epilepsy	
ID03	Shared house (temporary)	Ethiopia							
ID04	Bedsit Hostel	Nigeria	✓	PWUD		✓		Diabetes	INH
ID05	NFA	UK		PWID	✓				
ID06	NFA	UK	✓	PWID	✓		✓		
ID07	B&B Staying with relatives in their house	Somalia						Hypertension Diabetes Ulcer	
ID08	At risk as no recourse to public funds due to immigration status	Nigeria					✓	Drug induced diabetes	
ID09	NFA	UK	✓	PWID	✓			Hepatitis C	
ID10	NFA Hostel	Ethiopia							
ID11	NFA sometimes stays at a friend's house	UK				✓		Stomach ulcers	
ID12	B&B	Somalia							
ID13	NFA	Ireland				✓		Arthritis	
ID14	Hostel	UK	✓	PWID	✓	✓	✓		
ID15	Temporary bedsit	UK	✓	PWID	✓		✓	Hepatitis	
ID16	Hostel	UK		PWID	✓				INH
ID17	B&B	Somalia							INH

NFA= no fixed abode usually sleeping on streets; PWID person who injects drugs; PWUD person who uses drugs; OST Opioid substitution therapy (methadone); B&B an individual room to sleep where breakfast is sometimes offered. MXU mobile x-ray unit; DDU Drug dependency unit; INH Isoniazid; + did not have one main place of residence but would alternate;

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