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Chapter 5. Why do tuberculosis patients default in Tashkent City, Uzbekistan?: A qualitative study

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Summary

Background
Tuberculosis control in Tashkent City (Uzbekistan) is organized in accordance with the DOTS strategy. Intensive phase treatment is provided on in-patient, continuation phase treatment on ambulatory basis. In 2005, the defaulter rate was 21%. An earlier quantitative study revealed when patients default and identified some of the risk factors associated with default but did not answer the question: ‘Why do patients default?’ To further investigate reasons for defaulting and identify possible solutions, we performed a qualitative follow-up study.

Methods
We conducted 32 in-depth interviews with defaulters, patients who completed treatment and health care providers.

Results
Communication between patients and health services staff is poor. Patients lack proper information on TB and its treatment. There is a widespread belief that TB is not curable. Hospitalization is problematic because of poor general conditions in TB hospitals, costs incurred by patients while on admission, and because TB patients need to earn a living or take care of their families.

Conclusion
Poor communication between health services staff and TB patients is a key issue underlying several of the causes of default identified and needs to be addressed. Reducing the period of hospitalization too may improve adherence to TB treatment.
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Introduction

When patients are required to undergo lengthy treatments, such as in the case of tuberculosis (TB), poor adherence to treatment is a common problem\(^1\). This has also been observed in Tashkent City, capital of the republic of Uzbekistan. Upon independence in 1991 the country inherited the Soviet Union TB control system. This system had a strong focus on disease control and was characterized by active case finding and individualized in-patient treatment. As many other former Soviet countries, Uzbekistan witnessed a steep increase in TB case notification rates from the early 1990s onwards\(^2\). To counter this trend, Uzbekistan embarked upon a phased implementation of the internationally recommended DOTS strategy and achieved full DOTS-coverage in 2005. Case finding is now mainly passive and decentralized to general health facilities. In-patient treatment has been limited to the intensive phase, i.e. the first 2-3 months, after which ambulatory treatment continues for another 4-5 months. Out-patient treatment is provided three times weekly, under direct supervision of a health worker in specially designated rooms (DOTS corners) in general policlinics. Treatment regimens have been standardized. New patients are treated for 6 months; patients with a history of previous treatment are treated for 8 months. Many elements of the former system are still in place though, such as annual chest X-ray screening of the population and mandatory hospitalization during the first 2-3 months of treatment. Also the practice of keeping patients on register after completion of treatment and prescribing additional anti TB treatment courses in spring and autumn\(^3,4\) has been maintained.

The TB situation in Uzbekistan has improved since DOTS implementation. The annual TB mortality rate has decreased from 12.5 per 100,000 in 2002 to 8.5 in 2006. Case finding reached its peak in 2005 and there are indications of a moderate decline in incidence. For 2005 a treatment completion rate of 80.5% was reported nationwide with a defaulter rate of 6.8%\(^5\).

In Tashkent City, treatment completion rates are substantially lower than in the rest of the country, mainly as a result of high defaulter rates. In this study we define ‘Default’ as interrupting treatment for 2 months or longer, in accordance with the WHO definition\(^6\). Of 1087 pulmonary TB patients started on treatment in 2005, 228 (21%) defaulted. An earlier quantitative study showed that most of these patients (61%) defaulted during the intensive phase, while hospitalized. Another substantial part (26%) completed the intensive phase but did not initiate the continuation phase treatment; they were lost during their referral from in-patient treatment in a TB hospital to out-patient treatment at a TB dispensary. Most common reasons for default listed were ‘refusal of further treatment’ (27%) and ‘violation of hospital rules’ (18%). Unemployment, being retired and ‘alcohol abuse’ were statistically significant risk factors\(^7\).

Quantitative research may not be the most appropriate method to investigate treatment behaviour; the latter is a complex matter that cannot be explained solely by demographic and socio-economic factors\(^8\). Disease perception, health beliefs and subjective experience of illness also play a role. Therefore we conducted a qualitative study to identify and understand the reasons for default from TB treatment and find ways of addressing the problem.
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To structure our findings we used a framework described by Munro et al in a review of qualitative studies on adherence to tuberculosis treatment. Though the terms default and non-adherence cannot be used interchangeably, we considered default a form of non-adherence. The framework distinguishes structural, personal, and health service factors; the personal factors being influenced by the social context. The relation between personal factors and health service factors is assumed to be bi-directional with health service interventions directed at patients likely to influence patient adherence behaviour through the filter of personal factors; and patients’ interactions with the health services likely to be influenced by their knowledge, attitudes, and beliefs about treatment as well as their interpretations of illness and wellness (figure 1).

Figure 1 Model of factors affecting adherence‡‡

<table>
<thead>
<tr>
<th>Structural factors:</th>
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<tr>
<td>Incorporating poverty, especially costs and financial burden, gender discrimination, law</td>
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<th>Personal factors:</th>
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<td>Incorporating knowledge, beliefs, and attitudes towards treatment, interpretations of illness and</td>
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<th>Social context:</th>
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<td>Incorporating family, community and household support, including</td>
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<th>Health service factors:</th>
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<td>Incorporating organization of care and treatment, disease progress, and side effects</td>
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Methodology

We conducted 32 in-depth interviews with TB patients who defaulted from treatment (15), patients who successfully completed treatment (8) and health workers (9). The interviews were conducted in January/February 2007, by researchers of the National TB program of Uzbekistan (Republican DOTS Center) and the international non governmental organization (NGO) Project HOPE. All interviewers involved had a good background understanding of the social context and of how TB control is organized in Uzbekistan. They had undergone a one-week training in qualitative research and were supported throughout the study by a Tashkent based research agency (Expert Fikri). Although some of the interviewers were staff members of the Republican DOTS Center, none of them was directly involved in patient management. The role of the republican DOTS Center is mainly policy development and program management. Interviews were conducted in Uzbek and Russian depending on the language preferred by the participant.

We used a stratified purposeful sample taking into account the characteristics of particular subgroups of interest\textsuperscript{10}. Patients were selected from the TB patient registers of the Tashkent City TB services for the year 2006, aiming at an equal representation in terms of gender, age groups (below and above thirty) and defaulters and non-defaulters. Health workers were selected among doctors and nurses in TB facilities and doctors and nurses in general healthcare facilities in Tashkent city with the aim to represent the diversity of personnel involved in TB control.

Open-ended question guides were developed and field tested. The question guides were structured according to the flow of TB patients through the healthcare system. For TB patients the following topics were covered: healthcare seeking behaviour from the start of illness; information provided about the disease; treatment sites and methods; reasons for interrupting and/or stopping treatment (only for defaulters); and elements perceived as facilitating adherence to treatment. For the health services staff, the guide focused on reactions to TB diagnosis; information provided to TB patients and perceived barriers and enablers to treatment completion.

Interviews were recorded and transcribed verbatim. Analysis was done manually by two Russian speaking researchers (EH, MK), using a grounded theory approach, allowing relevant themes to emerge from the raw data during successive readings of the transcripts\textsuperscript{11}. Preliminary results were further discussed, refined and triangulated through 3 meetings of the whole research team. In addition, results were presented to and discussed with a sociologist not directly involved in the conduct of the study (PL).

The study was approved by the ethics committee of the Ministry of Health of Uzbekistan. All interviewees participated voluntarily. Informed consent was obtained and confidentiality was protected.

**Results**

Patients interviewed were equally distributed by gender and age group (above or below 30 years of age); there were 19 pulmonary TB cases and 4 extra pulmonary TB cases. Among the 15 defaulters, 3 defaulted during the intensive phase of TB treatment, while hospitalized; 9 completed the intensive phase but either did not start the (ambulatory) continuation phase (4/15) or defaulted 1-2 months later (5/15). Two patients never initiated treatment and one patient classified as defaulter had actually completed a full course of treatment. All patients interviewed had contacted the healthcare services at their own initiative.

The 9 health workers interviewed included 2 TB specialists, 2 general practitioners, 2 nurses from TB services and 3 nurses from general healthcare facilities.

Detailed results are presented in accordance with the conceptual framework described earlier.
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1. Personal Factors

Personal factors encompass knowledge, beliefs and attitudes towards treatment and interpretations of illness and wellness; as such they are important determinants of health care seeking behaviour and perception of disease.

Nearly all patients interviewed first presented at a general health care facility (policlinic), usually after having been seriously ill for quite some time.

'It all started in 2004, I lost weight till I weighed only 43 kg, I was very weak and I was coughing…’ (Woman, defaulter, 29 years old)

Upon being diagnosed as a TB patient, the initial reaction of most of the patients was either fear or denial. Most thought that they were going to die.

'I was frightened… better I go on hunger strike and die right a way. A neighbour of mine seriously suffered from tuberculosis. I know what kind of disease it is (Man, defaulter, 76 years old)

TB was often perceived as being incurable based on previous negative experiences with relatives or acquaintances that had died from TB.

'I think it's not curable, it can only be suppressed'. (Man, defaulter, 24 years old)

'I think tuberculosis is not curable… But if it was possible, first of all I would have wanted to cure my father... My father took treatment at home, he took all medicines, correctly, he did not take plantain§§ like me, he did not believe in it… a friend was treated in hospital, but it had no effect either… I think TB is not curable, very unlikely.' (Man, defaulter, 19 years old)

Findings from the health worker interviews confirmed to a large extent the findings from the patient interviews. Patients consider TB to be incurable and want to hide the fact that they have TB from their surroundings. General health services staff avoid talking to patients about TB.

‘...because these patients often refuse to accept that they have TB. There are some who even start shouting at us, they say that doctors do not know anything, that they cannot have such a disease.’ (Doctor in policlinic)

Whereas defaulters generally persisted in their initial belief that TB is not curable, most of those who completed treatment had become convinced that TB is curable. Usually this was the result of experiencing the effectiveness of treatment and of information provided by health workers.

'I thought it was like cancer, that patients will die anyhow. We did not know anything about this disease, only that others despise such patients. And when I was treated in the hospital, every day very ill patients died, mostly alcoholics. Later I was transferred to a normal ward, there nobody died, many were cured, then I started to believe that I would not die.' (Woman, completed treatment, 22 years old)

§§ A type of banana, generally used for cooking.
Yet even among those treated successfully, some believed that without further treatment their disease would come back.

‘Whether it is possible to be cured or not, I don’t know. When I was in the hospital I saw that some recovered but I’m not sure. I now have chest pains and I’m afraid to go to work. Last week I was in the TB dispensary and asked to be admitted to the TB hospital but they told me I first needed to make an X-ray before they would refer me’. (Man, completed treatment, 35 years old).

2. Health service related factors

Health service related factors include organization of care and treatment, disease progress, and side effects of drugs/treatment. Each of these themes emerged during the interviews. Side effects of anti-TB drugs were very often mentioned as the reason to interrupt treatment, though in many cases these appeared to be perceived rather than actual side effects. Problems with the liver were frequently mentioned; doctors prescribed specific treatment to protect the liver.

‘Many patients complained that these tablets have a bad effect on the liver, some affect the eyes, some the ears and some cause impotence. And I’m still a young man, of course I refused…’ (Man, defaulter, 45 years old)

‘But I did not take these tablets. I only took them for two months because they began to affect my liver’. (Man, completed treatment, 30 years old)

‘For the liver, I was put on a drip’. (Woman, defaulter, 29 years old)

‘They do not like DOTS treatment, they say they cannot tolerate these tablets, they show skin rashes or complain of stomach and liver problems.’ (Nurse in TB dispensary)

Unwillingness to be hospitalized was another recurrent theme. Patients were reluctant to be admitted because of perceived bad hygienic and general conditions in TB hospitals.

‘I did not like the hospital. I did not like it there at all. It’s full of criminals. All the walls are filthy, it’s despicable. You cannot even sit on the toilets.’ (Man, defaulter, 25 years old)

‘But it is such a dirty hospital, all the time I was washing myself with soap. Fortunately I had a room of my own.’ (Woman, defaulter, 35 years old)

‘But I did not agree to be admitted there because most of the patients are former convicts, it’s a filthy hospital and it’s far from our home.’ (Man, defaulter, 47 years old).

The attitude of health workers was mentioned as an important issue both by patients and health workers themselves. For some patients the bad attitude of health workers was a reason to interrupt treatment; on the other hand there were also patients with
very positive experiences. Negative attitudes towards TB patients among health workers appear to be related to the fact that health workers often associate TB with an anti-social lifestyle, i.e. alcoholism, drug abuse, delinquency. Staff of general health facilities express reservations with treating TB patients because of perceived infectiousness.

‘In general doctors and nurses in the TB hospital were so kind and interested, we were really surprised’. (Man, completed treatment, 22 years old)

‘I did not want to go to the polyclinic because there the attitude of doctors towards patients is bad. I felt hostility towards myself, even though after the operation I was cured, still there was some sense of hostility.’ (Woman, defaulter, 24 years old)

‘I think most cases of tuberculosis occur among former prisoners. But for continuation phase treatment we also get decent people, I was surprised, how did they get tuberculosis? Could it be because they smoke?’ (Nurse in polyclinic)

‘And the nurses in the policlinics themselves tell us that they don’t like to see this kind of patients. I understand them very well. You see in the corridors of such policlinics, there are also newborns. This mixing of patients is not right.’ (Doctor in TB dispensary)

Most patients, including those who completed treatment, did not know the correct duration of treatment. Though the treatment duration for new TB patients has been standardized at 6 months, only 3 patients who completed treatment were aware of this. By and large, health workers knew the correct duration of treatment but their messages to the patients were often not very clear. Most did mention the two stages of treatment, in-patient and out-patient treatment. However some included the follow-up period after treatment, whereas those working in hospitals tended to focus on the duration of treatment in their facility. Treatment durations mentioned thus ranged from 2-3 months to several years.

‘They did not tell me how long I should take tablets, they just said: ‘Until we remove you from the register.’ (Woman, defaulter, 29 years old)

‘To new patients I say that they will be treated by us for 2 months. After checking whether there are no more bacilli, we will discharge you and afterwards at the dispensary they will decide how long you should still be treated, how long you will remain on register.’ (Nurse in TB hospital)

‘New patients are treated for about one year. They are checked quarterly. The TB specialists advise us and write referral letters. If it is a patient with an advanced form, then of course longer.’ (Doctor in polyclinic)

Even after patients have been cured, they are kept on register and are being prescribed additional treatment.

‘Yesterday I also went to the dispensary and they did the investigations; they gave me white tablets and told me to come back in one week. Until February they will keep
me on register, and then they will remove me from register.’ (Woman, completed treatment, 20 years old)

‘After this (treatment) they advised me to take Isoniazid tablets 3 times a week in spring and autumn’. (Man, completed treatment, 50 years old)

Information provided by health workers on other aspects of TB treatment was also often incomplete or incorrect. A theme frequently mentioned was infectiousness of TB related to the need for hygiene; patients were told to maintain good personal hygiene and to use separate cutlery and crockery in order not to infect those around them.

‘We explain to them the rules about hygiene, that they should have separate cutlery and crockery….. Also they should think not about themselves in the first place but about us, and about the children, about the relatives; that they should not spread the infection to their relatives.’ (Nurse in TB hospital)

Defaulters did often continue treatment for a while on anti-TB drugs bought from private pharmacies. Such treatments were usually prescribed by a TB doctor but taken irregularly and without supervision.

‘After they discharged me from hospital I continued taking tablets but I bought them myself. I did not want to travel up and down; I live with my family in Yunusabad but was treated in Lysunova because that’s where I’m officially registered’. (Man, defaulter, 24 years old)

3. Structural factors
Among structural factors, both direct costs and opportunity costs emerged as important obstacles to completion of anti-TB treatment. Though TB drugs are provided free of charge, patients do have to buy additional drugs. As most patients are employed on an informal basis, being absent from work means not having any income and the risk of losing one’s job.

‘It’s lack of money. Well everywhere they write that TB treatment is free of charge. And where is it free of charge? Only tablets they give for free. Everything else we have to buy. – injections, drips…and then, who will feed my children? I don’t have a job, I do not receive a pension. I live from what I can earn on the side’. (Woman, defaulter, 42 years old)

‘I have to feed my wife and two children; my work is very important to me, I work in building construction, I’m not employed by the government so I don’t have to hope for paid sick leave….’ (Man, defaulter, 24 years old)

‘The problem is that many patients are the sole bread winner, they don’t manage to complete treatment, they’re in a hurry to get back to work….’ (Nurse in TB hospital)

4. The social context
The social context which includes family, community and household support, including stigma, also emerged as an important determinant. Most patients decided not to disclose the fact that they were suffering from TB except to their closest
relatives. Yet contrary to the expectations of the patients themselves, these relatives were usually very supportive. Nevertheless patients feared being ostracized and also there was the fear of infecting others.

*I wasn’t just afraid for myself, I thought that if the neighbours knew they would start fearing and avoiding me.*’ (Man, defaulter, 76 years old).

Some patients were reluctant to go to the policlinic for TB treatment because they were afraid of being recognized by neighbours, this was also mentioned by health workers.

*My mother brought the tablets from the policlinic. I myself was hesitant to go to the policlinic in case someone would see me.*’ (Woman, completed treatment, 22 years old)

*‘The same policlinics are visited by their neighbours and the probability of meeting someone you know is 80%. All patients are afraid to meet their neighbours.’* (Doctor in TB dispensary)

A doctor in one of the TB hospitals observed that women with young children were often under pressure of their husbands to return home and take care of their children.

*‘Especially among women – married women default because of family circumstances. Their husbands come and start shouting, ‘How much longer does my wife have to be treated?’ You see, the children are on their own.’* (Doctor in TB hospital)

**Discussion**

In their comprehensive review of three decades of research into patient adherence, Vermeire et al\(^{12}\) state that although many studies have investigated causal relationships between patient factors, doctor factors and adherence, no consistent story has yet emerged. Their conclusion is that adherence is not determined by the nature of the disease, the referral process, the clinical setting and the treatment regimen, and that demographic and social factors too are poor indicators of adherence. The most salient influences on adherence in their view are the patients’ beliefs about medications and medicine in general, as well as those of family members and friends. They emphasize the importance of the doctor-patient relationship in which the patient’s autonomy and right to self determination must be respected. The role of the doctor should be that of an expert advisor but it is ultimately the patient who decides what is in his own best interest. Communication between doctor and patient is thus of key importance.

Results from our study confirm the importance of the doctor-patient relationship but we did also identify a few other factors that appear to be important in the particular setting of a post Soviet country. Our findings fit very well in the general framework described by Munro *et al.*\(^9\) which is an indication of its relevance. The most prominent personal factor to emerge is lack of knowledge about the disease and its treatment, which confirms the importance of individual patients’ beliefs described by Vermeire et al. Many do not really believe that TB is curable and therefore do not see the need for prolonged and regular treatment. In addition to this, most patients do not
know for how long they are supposed to be treated. Our results also clearly indicate that these personal factors are very often being reinforced by health services related factors. This strong association seems related to the particularities of the setting. The former Soviet Union is a very specific setting and several earlier studies also identified health service related and structural factors as important determinants of non-adherence\textsuperscript{13,14,15,16}.

Considering the long period patients spent in TB hospitals, their lack of knowledge could be considered a health service related factor because there had been ample time for health workers to educate them. Poor communication between health services staff and patients is not unique to the TB system in Tashkent but has also been observed in other former Soviet Union settings\textsuperscript{17,18}. Moreover part of the information patients did receive was incorrect or inappropriate.

Even among health workers there is no clarity about the duration of TB treatment. A possible explanation may be in the conflicting guidelines. Treatment regimens in Uzbekistan have been standardized in accordance with the DOTS strategy but as mentioned in the introduction, the old guidelines are also still in place\textsuperscript{19}. These prescribe a follow up of at least 2 years after cure, including biannual courses of chemotherapy in spring and autumn.

Intolerance to anti-TB drugs is another area where health service factors and personal factors interact. Many defaulters mentioned intolerance to anti-TB drugs as an important reason to stop taking them; there was a particular concern about damage to the liver. Although hepato-toxicity is a known side effect of some anti TB drugs, it is not as common as patients apparently assume\textsuperscript{20}. There is thus an urgent need to properly inform patients on the potential side effects of anti-TB drugs because on most occasions they can be managed and do not need to lead to interruption of treatment\textsuperscript{6}.

The attitude of health services staff was mentioned by health workers and patients as an important factor contributing to default. Here again health services factors and personal factors interact as there were positive as well as negative experiences. Negative attitudes among health services personnel are often related to their perception of TB being a disease of the socially marginalized. General health services staff often do not welcome the idea of treating TB patients because of the perceived danger of infectiousness. Health workers pay a lot of attention to hygiene as a way to prevent transmission of TB and recommend irrational and stigmatizing measures such as using separate cutlery and crockery.

Finally, mandatory hospitalization during the first phase of treatment is an important health services factor negatively affecting adherence. Some patients do not start treatment at all to avoid being hospitalized; others leave the hospital either because they are appalled by the prevailing general and hygienic conditions, or because they cannot afford to stay without earning money or taking care of their families. Moreover they incur substantial costs because of having to buy additional non-TB drugs. In the days of the Soviet Union income was guaranteed and hospitals were well maintained and well supplied; being on admission was therefore not a major problem\textsuperscript{21}. The structural context has changed with the collapse of the Soviet Union; TB patients can
no longer afford not to work and underfunding of health services has resulted in poor conditions in hospitals\textsuperscript{2,22}.

Hospitalization is often defended as a public health measure aimed at interrupting transmission of tuberculosis. The Madras study in 1959 clearly demonstrated that transmission to close contacts usually happens before the index case is diagnosed and that hospitalization itself does not reduce transmission\textsuperscript{23}. More recent studies from countries of the former Soviet Union show that the majority of admissions for tuberculosis are unnecessary when clinical and public health criteria are applied\textsuperscript{24,25,26}. Restricting hospitalization to those cases where there is a clinical need or to the first 3-4 weeks for those being smear positive would make the system much more client friendly.

Among factors related to the social context, stigma was most often mentioned. Patients fear being ostracized both because of TB being an infectious disease and because of TB being perceived as a disease of criminals and other socially marginalized individuals. Often the stigma appears to be felt rather than enacted, i.e. the fear of being stigmatized rather than actually being stigmatized\textsuperscript{27}. Nevertheless it is obvious that both the public and health workers have a low opinion of TB patients, reflected in their being surprised by the fact that even ‘decent’ people can suffer from TB.

**Limitations**

This is a qualitative study, aimed to explain, and not quantify, the phenomena observed. The study took place in an urban setting; for some aspects conditions prevailing in rural settings may be different.

**Conclusion**

We identified several factors that lead to default; many of them related to the health system, often in interaction with personal factors. The current TB control system in Uzbekistan is still very much provider and disease control oriented. Conflicting guidelines lead to a lack of clarity, even among providers. An important underlying cause is the fact that health care providers are often not inclined to communicate with TB patients. As a result TB patients lack a clear perspective on their disease and its treatment.

In response to the results of this study, a training program on counselling skills for nurses of TB hospitals in Tashkent has been developed. These nurses were provided with standardized messages to be communicated to TB patients.

The underlying problem of non-uniform treatment guidelines still needs to be addressed. This includes the practices of prescribing additional non-TB drugs and preventive anti-TB chemotherapy in spring and autumn.

Hospitalization itself leads to default because of poor in-patient conditions and because patients need to earn a living or take care of their families. To structurally improve conditions in hospitals may prove to be very costly. A more feasible solution would thus be to promote ambulatory treatment at an earlier stage.
Various structural and health system factors need to be addressed but the key issue appears to be improving the communication between health services staff and TB patients, allowing patients to make an informed decision on what’s in their own best interest.

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