

# Barriers in the Management of Tuberculosis in Rawalpindi, Pakistan: A Qualitative Study

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**Background:** Tuberculosis (TB) is a contagious, airborne disease and remains a major global public health hazard. TB is a major cause of mortality and is affecting millions of people in low-income and middle-income countries. Worldwide, one person out of three is infected with the *Mycobacterium tuberculosis*. Timely diagnosis and treatment are the two key factors for better outcomes. Non-adherence to TB treatment is an important barrier for TB control programs. This study was designed to understand the barriers encountered by TB patients when seeking health care.

**Materials and Methods:** A qualitative study was conducted during the months of August and December 2010 on 15 health facilities. In-depth interviews were conducted with 23 TB patients (13 males and 10 females) aged 15-65 years. In addition, 15 health personnel were also interviewed.

**Results:** Most patients were found to be well informed about the idea of taking TB medications under direct supervision and its overall importance. However, many of them were not convinced with either drugs or treatment protocols. We found that limited knowledge of patients, loss of employment, financial burden, social stigma and long distance from health facility were the main barriers for TB adherence.

**Conclusion:** More patient-centred interventions and attention to the barriers are required to improve the treatment adherence. Direct observation of patients and regular home visits by health workers can reduce the risk of non-adherence.

**Key words:** Tuberculosis, Qualitative study, Delay, Stigma, Rawalpindi, Pakistan.

## INTRODUCTION

Tuberculosis (TB) is a contagious, airborne disease and remains a major public health problem despite the recent progress of global efforts. TB is a major cause of morbidity and mortality, affecting millions of people in the developing countries. In 2011, there were an estimated 8.7 million new cases of TB and 1.4 million people died from TB (1). Worldwide one person out of three is infected with *Mycobacterium tuberculosis*.

Directly observed treatment short-course (DOTS) is an internationally recommended treatment strategy for TB patients. Timely diagnosis and treatment of TB are the two key factors for better outcomes. Treatment requires access to appropriate health care, but many patients may find it difficult to comply with the treatment even when such services are available. Non-adherence to TB is an important barrier for TB control programs. Incomplete treatment may

result in prolonged infectiousness, relapse, drug resistance and death (2). This requires a better understanding of the barriers and enablers in order to improve the treatment outcomes through patients and treatment providers (3).

World Health Organization (WHO) in 2006 launched “The Stop TB Strategy” as an evidence-based approach to reduce the burden of TB with provision of supervision and patient support based on effective two way communication between healthcare providers and those receiving treatment (4). This patient-centred approach is also reflected in the International Standards for TB Care (5). Increased empowerment may reduce the burden on patients, increase case detection and promote treatment completion (6). This study was designed to understand the barriers encountered by TB patients when seeking health care.

## MATERIALS AND METHODS

This study was carried out in the District Rawalpindi, Pakistan. District Rawalpindi is located in the north of Punjab Province and next to capital city Islamabad. It covers 108.8 square kilometers. The TB DOTS programme was implemented in the District Rawalpindi in 2003. The national program achieved 100% TB DOTS countrywide coverage in all public sector health facilities in 2005 (Figure 1).

This qualitative study was conducted during the months of August and December 2010. The data were collected from 15 health facilities and the purpose was to understand the barriers encountered by TB patients while seeking health care in order to know patients’ perspectives and experiences with health care staff, treatment supporters, their attitudes, social pressures, access to health services and economic support which influence patients’ compliance to treatment. The study also aimed to understand the treatment providers’ (DOTS facilitators) perspectives and experience regarding treatment support (knowledge and processes involved in offering treatment support) and to get suggestions to improve treatment support process. The questionnaires in English were

translated into Urdu. The questionnaires had semi-structured, open-ended and closed questions.

### *Participants and data collection*

A random sample of 30 TB patients was selected for in-depth interviews after grouping them according to their type of treatment outcome. In order to select patients for the in-depth interviews, health facility registers (TB registers TB03) were used. These patients were then approached and finally 23 patients (13 males and 10 females) aged 15-65 years were interviewed. Four (4) patients from unfavorable group (including failure and defaulted cases) were not accessible; address of one patient was wrong while three patients refused to give interview. Addresses of 3 patients were wrong among treatment success group (cured and treatment success cases). There were 15 participants from urban and 8 from rural settings.

In addition, 15 in-depth interviews were also conducted with DOTS facilitators, 5 from urban settings and 10 from rural settings; 4 participants were females from rural settings, while 11 participants were males, 6 from rural and 5 from urban settings. The age range was between 21-47 yrs., with 1-8 years of experience as DOTS facilitator. The majority of them had 2 years of experience. All participants had attended the training course on TB DOTS paramedic’s module.

The entire interviews were recorded in writing, which were then translated to English, transcribed verbatim, coded and were categorized into main themes. The study was approved by the National Bioethical Committee (NBC) of Pakistan. Confidentiality was ensured by not disclosing the identity of participants and written informed consent was obtained from all patients.

All the interviews were conducted by the principal author. Urdu language was used for interviews, which allowed communication between the researcher and information provider and this also reduced the misunderstanding between the interviewers and interviewees. Thus, if the interviewee did not understand

the question, the researcher could explain the question and obtain relevant data.

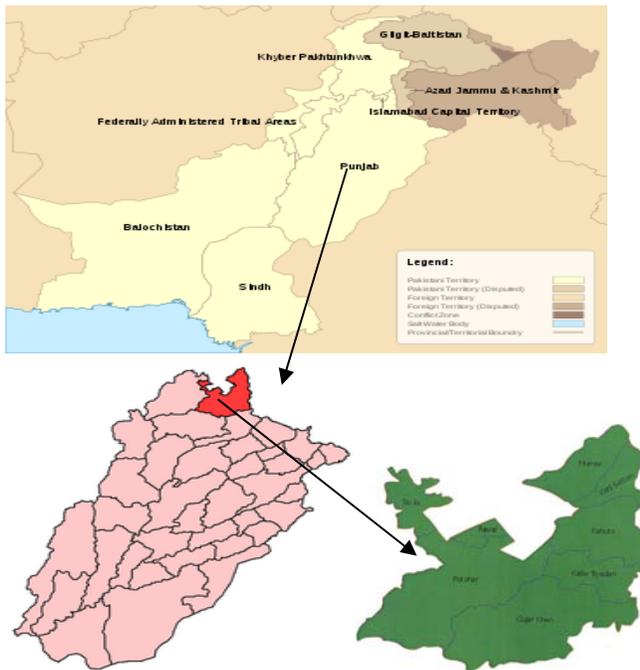


Figure 1. Map of Pakistan (pointer showing the study district)

## RESULTS

### Patients' perspectives and experience:

#### Treatment success group:

The majority of patients were found to be well informed about the importance of taking TB medications under direct supervision and seemed to be convinced. They believed that this strategy made their life easier in relation to TB treatment. Most patients were convinced that the difficulty related to collection of drugs has been addressed since someone else has taken this responsibility. Few of the patients mentioned the long distance to the hospitals and that they no longer needed to commute to get their drug. Some of them stated that this is the reason for their compliance to treatment

Almost all patients were regularly taking drugs. Most of the patients especially with family members as their treatment supporter reported no complaint regarding behavioral problems or even problems related to gender, timing of drug intake or availability issues. However, few

of patients were a bit skeptical about the timing and availability of community health workers / lady health workers. They sometimes had to wait to get drugs from the community health workers / lady health workers. This issue was managed by most of the patients by scheduling the time for the home visits in advance.

Patients having family members as treatment supporter reported getting social support in terms of motivation reassurance and sharing of work. Some of these patients also reported getting some sort of financial support mainly in the form of cash.

*"My father used to give me cash to buy cloths and for travelling expenditures as I lost my job due to ill health". (Patient)*

Almost all patients reported going to the health facility on a monthly basis either with or without the treatment supporter for drug collection and follow-up visits. Regarding the patient and treatment supporter arrangements in the case of leave, none of the patients reported facing any inconvenience. One patient shared the information that:

*"My treatment supporter used to give me medicines regularly and never left without giving me the medicines and in case of emergency situation they used to give the responsibility of giving drugs to their family members". (Patient)*

#### Unsuccessful group

Interestingly, most of the patients in the unsuccessful group were found to be well informed about the idea of taking TB medications under direct supervision and its overall importance. However, many of them were not convinced with either drugs or treatment protocols. According to them, the medicines were difficult to take and they had doubts regarding their efficacy. One of the patient's relatives died of TB. He was not convinced and said that:

*"These medicines do not work regardless of the way you take them". (Patient)*

Almost all patients were found to be irregular in taking TB drugs. One patient responded as:

*"I discontinued treatment because after two months I felt better and I thought I was cured". (Patient)*

Few patients were not convinced to have a treatment supporter. One patient responded as:

*"If I am provided with a treatment supporter then other people will find out about my illness". (Patient)*

Most of them only collected their first batch of drugs and never opted for the next batch. Few of the patients did raise issues about the attitude of family members but none were serious. Regarding the community health workers / lady health workers they all had issues about their performance as treatment support.

*"I was asked to contact LHW in my area. I contacted her but she never came to see me". (Patient)*

Loss of employment was found to be one of the main barriers for TB adherence. According to the patients in this group they did not receive any type of social or financial support from the supporters; they believed that:

*"People are sympathetic but these are just words, no one came forward to help me financially". (Patient)*

Almost all patients reported that after the first two or three visits to the hospital they never went back. Few of them sought help from hakims or homeopathic medicine.

#### *Treatment Providers' Perspectives and Experiences*

All the DOTS facilitators were found informative and were clear about the process of selection of treatment supporters for patients. Almost all participants stated that they did not face any problem during information sharing and convincing patients for having a treatment supporter except a few. One participant said:

*"Some patients do not want to disclose their disease to others and thus they do not want to have a treatment supporter". (DOTS facilitator)*

Another participant stated that:

*"Many patients try to hide their disease and that is why they do not agree to have a treatment supporter other than their family members". (DOTS facilitator)*

Ideally, the patients should be given the option to select their treatment supporter. All the participants were expressive and provided mixed information; some said that they provide this opportunity to patients to select their own treatment supporter while some others said that they

decide by themselves who should be the treatment supporter for patients based on the patient's place of residence. One participant said:

*"I cannot provide too many options to patients, most of the times I choose a treatment supporter by myself for the patient like, LHW and then give priority to a family member or a community volunteer". (DOTS facilitator)*

Another participant said:

*"It depends on the situation, I give options to the patients and most of the time they prefer their family members as treatment supporter". (DOTS facilitator)*

Another participant said:

*"This is a mountainous area, so it is not good for patients to have a treatment supporter who lives far from here; thus I ask patients to choose their own treatment supporter". (DOTS facilitator)*

It was observed and also showed by participants that they had a list of contact numbers of the LHW, CVT, and HFW working in the catchment area of their health facility. One participant stated that:

*"I contacted treatment supporters by phone, I have the contact list (showing the charts on the wall) of all LHW and CVT". (DOTS facilitator)*

Few suggestions were given to improve the treatment support process, including the training of different treatment supporters including LHW, CVT, and CHW and giving incentives to DOTS facilitators and treatment supporters and also counter checking of treatment supporters.

## DISCUSSION

History reveals that many efforts have been made to overcome TB (7-9). The fight is not over yet in most developing countries. With the invention of new diagnostic tools and treatment regimens we can cure a TB patient; but that is not what it is all about. TB should be eradicated. This requires not only diagnostic and treatment protocols but also a comprehensive control program with clear and effective strategies, commitment of the authorities, secured funds, trained health care providers, effective registry and

reporting instruments and above all a changed public attitude towards a healthy society.

In Pakistan the availability of health care services and infrastructure has never been a big problem. There is an established system of primary, secondary and tertiary level health care facilities which is further supported by more than 1,00,000 lady health workers and other community health workers (10). Also, a huge number of private care providers are available mostly providing the first level of care for almost all types of health problems. The problem is to make these services more effective. This can only be achieved if the health problems in Pakistan be dealt with in a holistic way supported by both macro- and micro-level planning.

Early detection of TB patients and providing effective treatment are required to prevent the spread of disease (11), but long term anti-TB therapy can lead to patient non-adherence (12). A recent study conducted in India showed different pathways taken by TB patients while seeking medical care (13). There are various factors involved in the adherence to anti-TB treatment that are important barriers for TB control programs. These various factors may be grouped as: personal factors, family factors, social factors, and health system factors (6, 11-16). These factors also vary in different populations and may be different or similar to our study.

A study among Somali pastoralists in Ethiopia, showed that the traditional beliefs and seasonal migrations restrict their access to health care services (17). Another study from rural Ethiopia, found that long distance from health facilities, financial burdens, use of traditional healing systems and delay in diagnosis by health care providers were the main reasons for not initiating a timely TB treatment (18).

Financial burden is one of the issues associated with non-adherence and was highlighted in our study. Other studies also found the financial constraints as a common barrier for anti-TB management (18-21). Similarly, a study

from China showed that economic burden and political disinterests might act as a barrier in some areas of China (22).

Stigma of having TB is another common obstacle documented in other studies as well (23-26). Being female is another issue associated with inefficient TB diagnosis and treatment. In rural areas, only a minority of female population may have access to the health system resulting in an under-reporting of disease in female population. The reason for this is the socio-cultural environment in Pakistan mostly in the rural setting. Similar findings were also observed in a study in Peru where women's TB care was of secondary importance to that of men (27).

In our study, most patients especially with a family member as treatment supporter reported no complaints regarding behavioural problems or even problems related to gender, timing or drug intake or even availability issues. However, regarding community health workers/lady health workers they had some issues about their performance as treatment supporter. None of the defaulted patients received any type of social or financial support from the supporter.

Attention should be paid to strategies to improve treatment adherence for reducing the perceived barriers by making the treatment more accessible, affordable and culturally acceptable. Enhanced role of social networks in providing psychological, financial and service support to TB patients, during the whole treatment, is another potential area where further attention is needed to improve the care of TB patients.

A post-trial qualitative study carried out in Pakistan (28), showed that health workers were unsatisfied and non-committed to their profession and not convinced with the idea of DOTS. In that situation it is a challenge to enhance the capacity and the commitment of the care providers for quality care delivery to TB patients. In a qualitative study in Senegal (29), the obstacles against successful outcomes were identified at various levels of health care; these obstacles included: limited access to TB diagnosis and treatment facilities, poor communication

between health personnel and patients, low quality information provided by patients, poorly applied DOT, and lack of strategy to trace defaulting patients. A study conducted in India (30) also found similar results as in Senegal.

Watkins et al. conducted a study in Bali, Indonesia (31), to know the barriers and improve TB treatment. The care providers interviewed included doctors, nurses, health workers and laboratory analysts. Lack of community awareness about TB, delay in treatment seeking and frequent use of private treatment providers, diagnostic difficulties and low level of staff education related to TB were the main findings of the study.

In our study the care providers were found to be committed to the DOTS care delivery and despite of their huge work load at the hospital they managed to provide information to the patients during the treatment supporter selection process.

This study was conducted in only one district of Pakistan. Although we studied only one district, we selected health facilities which were under DOTS program in public sector. However, the situation in other districts is more or less the same.

## CONCLUSIONS

More patient-centred interventions and attention to the barriers are required to improve the treatment adherence. Direct observation of patients and regular home visits by health workers can reduce the risk of non-adherence.

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