



This Special Series depicts the efforts made by the patients and health workers to tackle TB. Through this document, we reflect the efforts made by the government for the management of MDR TB in Nepal and hardships faced by the patients during the long course of treatment. The health seeking behaviour of the patients, the willingness to continue the treatment, the social stigma they have faced and their economic hardships have been documented. We also share perspectives of the health workers and the patients about how they view the MDR TB interventions.

MULTI-LINEARITY OF MDR TB: THE NEPAL STORY A FIELD VISIT REPORT



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Introduction

TB is one of the major public health problems in Nepal, causing a significant burden of morbidity and mortality. About 45 percent of the total population is infected with TB, out of which 60 percent are adults. Every year, 40,000 people develop active TB, of whom 20,000 have infectious pulmonary disease. These 20,000 are able to spread the disease to others. TB causes estimated 5,000-7,000 deaths per year. The bacteria that causes TB can develop resistance to the antimicrobial drugs used to cure the disease. Multidrug-resistant TB (MDR-TB) is a type of TB that does not respond to at least isoniazid and rifampicin, the two most powerful anti-TB drugs (WHO). Extensively drug-resistant TB (XDR TB) is a rare type of multidrug-resistant tuberculosis (MDR TB) that is resistant to isoniazid and rifampin, plus any fluoroquinolone and at least one of three injectable second-line drugs.

Government of Nepal has made several efforts to curb TB in Nepal. Health facilities - district hospitals and primary health care centres are the basic units for TB diagnosis and treatment. Free anti-tuberculosis treatment is provided to all patients with active tuberculosis as part of the basic health services, with a priority for sputum smear-positive cases. Evaluation by four monthly cohort analysis of treatment outcome to monitor the progress and efficiency of TB treatment has been put into practice. Community involvement for DOTS implementation has also been carried out. Although TB treatment is available in numerous hospitals and health centres, **MDR TB treatment is available only in 13 centres and 73 sub centres throughout the country.**

Drug resistant TB (DR-TB) is an increasing threat to the success of global TB control. Treatment currently takes a minimum of 20 months and requires careful supervision and patient support to identify problems associated with treatment and to ensure patients complete treatment. In Nepal, 2.9% of new TB cases, and 12% of previously treated cases, are DR-TB. According to the National Tuberculosis Centre, “The number of multi-drug-resistant tuberculosis patients has been increasing. A total of **379 multi-drug resistant TB cases were detected in 2015.**”

Although the National TB Programme (NTP) provides free drugs, the treatment is long and unpleasant causing a huge socio economic burden on the patients and their family members. Supervision and support for patients though crucial, the national guidelines for DR-TB management do not talk much on this component.

Methods

HERD team conducted a field visit to Rupandehi in April 2016 as part of implementation of the project, “Improving supervision and patient support approach for drug resistant TB patients in Nepal”. During the visit,

HERD team conducted interviews and informal interactions with the patients and the health workers. The patients were identified with the help of DOTS In-charge at the Lumbini Zonal hospital and the interviews conducted with patients at the Rupandehi DR-TB hostel and Lumbini Zonal Hospital. The DOTS In-charge and other health workers were also interviewed. The interviews were recorded with the permission of the patients and health workers and the photographs were also taken with their consent. Taking into account the sensitivity of the issue, ethical approval was received from the Ministry of Health. The interviews conducted were transcribed and an analysis framework was developed. Grounded theory

approach was used where the codes were generated based on the interview transcripts. From the codes, various themes were generated such as symptoms, health seeking behaviour, out of pocket expenditure, social stigma, awareness, government support, among others. The table below shows how transcripts were categorized into themes based on the codes. The quotes were placed according to various themes which were then explained in the narrative form and the report was generated.

The names of the patients and health workers have been anonymised for confidentiality. We talked to seven patients, three health workers and family member of a patient during our visit.

Theme	Patient 1	Patient 2	Patient 3
Social Stigma	No one near the rented room was aware of my disease. If they had known about it there is no way I would have got one. People have such negative opinion about the disease that it will be transmitted immediately so at that time I didn't disclose about my disease. I lied that I suffered from other disease and I did some other job.	For me living in hostel like living in the jail. While walking outside people came to cover my face. I wish no one suffers from the disease in the world.	My family and neighbours behaved well with me. I didn't notice any change in their behaviour when I was detected TB.

Perspectives of Patients and Health Workers

Knowing you have the disease

The patients highlighted various physical and some psychological problems they experienced before getting tested for TB like **headache, cold, dry sensation in the throat, mild fever, weak digestion, loose motion, weakness, dizzy, blood in cough, change in skin colour, rise in blood pressure, back ache and pain in hands and legs**. The problems also varied while being treated for TB and MDR TB.

P1 (Male, 33) - "My face became black and I had constant cough and fever. I used to feel hungry, dizzy and my blood pressure would rise. I used to be angry all the time."

P2 (Male, 42) - "When I suffered from TB it wasn't that difficult, may be it was due to the short duration of treatment. But since I suffered from MDR TB, I have been having various problems, back ache and pain in hands and legs."

The patients preferred going to the nearby medical store (generally called medicals) for checkup when they experience symptoms. Only when the medicine showed no response, the patients considered going hospitals. Furthermore, private hospitals were their first choice of health facilities **rather than government health facilities**. After being referred from the private health facilities, the patients came to the government hospital to receive service from the DOTS clinic.

P3 (Female, 33) - "I did a lot of check-up at the medicals nearby but nothing was detected. As the cough didn't get any better I came to Butwal and did check-up still nothing was seen. Then at one of the medicals, TB was detected. I had medicine for three months but there was no improvement and then I visited Lumbini Zonal Hospital where MDR TB was detected."

P2 (Male, 42) - "I went to Palpa Missionary Hospital for check-up, they did many tests and then they recommended me to Lumbini Zonal Hospital as I lived in Butwal."

At Lumbini Zonal Hospital, one to two new patients of TB are detected every day. They are referred to the nearest DOTS centre where they are provided with some information and enrolled in the treatment. Most of the patients preferred getting treatment in the health facilities where they had received the service earlier.

Fear Factor

Every patient has his/her own experiences on how the society viewed them. Patients were found hiding that they were suffering from MDR TB. The only one aware was the health worker and the family member which helped the secret to 'remain within the family'. Furthermore, in many cases, patients hide it even from their family members and community in the fear of stigma and discrimination.

P4 (Male, 22) - "When I suffered from TB, no one except the health worker and my family member knew about it. I told everyone in the community that I was suffering from pneumonia because if they knew about my disease they would disregard me. Even now when I am suffering from MDR TB only my family members, few close relatives, neighbours and friends know about it."

The attitude and behaviour of the people was different for general TB and MDR TB patients. **While suffering from TB, the society wasn't different but later when the same person was detected of MDR TB, the neighbours and friends were not welcoming them anymore.** In such a scenario some of patients were found seeking shelter away from home and also in the hostel. In many cases, patients don't want to be seen while taking general Tb medicines because it is a short course treatment and they don't want to reveal their TB status.

P5 (Male, 26) - "When people say anything I hear it from one ear and let it go from another. If they talk about good things I remember it but if I hear some negative remarks I act like I never heard it. When I had medicine for six months everyone's reaction was normal but when I was detected MDR TB, I started losing friends. "

P6 (Male, 23) - "When I started the treatment, I used to fear visiting the hospital that the people might recognise me. I was scared what will happen if the people of my community knew that I was suffering from MDR TB."

Not all patients could get hostel facility. Some of those who have been receiving treatment at the hostel struggled at the beginning. Till the time a room was available at the hostel they had to stay near the hospital so that they could go and have the medicine daily. Finding a room in such a crowded city is difficult and when the person is suffering from TB, it is impossible. **Most of the patients were found lying about the disease due to fear of shame. Even while walking around in the neighbourhood of the hostel, they felt guilty seeing the negative attitude of the people.**

P4 (Male, 22) - "No one near the rented room was aware of my disease. If they were aware there is no way I would have got a room. People have such negative opinion about the disease that it will be transmitted immediately so at that time I didn't disclose about my disease. I lied that I suffered from other disease and I did some other job so that I could get a room. "

P7 (Male, 48) - "For me living in the hostel is like being in a jail. Even if we go out for a walk, the people of the neighbourhood come to cover my face. I wish no one in the world suffers from this disease."



The society didn't behave the same way to all the patients. Some patients never faced any kind of social stigma. They received support from the family, friends as well as the community which had a positive impact in their treatment.

P6 (Male, 23) - "When I got the disease everyone my family, neighbours and my friends were supportive. No one gave me negative remarks outside. My friends used to visit me at my house. Even at work I never experienced any objectionable behaviour from any co-worker".

Tackling the situation

The patients complained about various side effects they faced after beginning the treatment. They have felt changes physically as well as mentally. While continuing the treatment, patients have noticed weakness, dizziness, stomach ache, pain in various parts of the body. They also had mental stress and various psychological problems, as reported by the health workers.

The patients suffering from MDR and XDR as well as the patient whose disease was detected late are found having various thoughts. They are found taking stress and having the fear that the disease might be occurring again.

P3 (Female, 33) - "In the beginning I had pain in hands, legs and chest. It was very difficult because when I started medicine and made up my mind that I am suffering from MDR-TB I was informed I had XDR TB. It has been very difficult I feel like I might never be fine again"

When the treatment begins, the patients start having various thoughts. During that time talking to someone sharing their feeling is very important. The patients themselves feel that the side effects sometimes make the person depressed. **Some of the patients have also felt the change in the skin colour which creates fear among them if they will ever be cured, which also makes them feel like discontinuing the treatment.**

P5 (Male, 26) - "When you start having medicine for TB one should not stay alone as you get many thoughts like how I suffered from disease, what can I do, will I ever be fine, how did it happen, how long will I live? You shouldn't think like this. You should have medicine, proper diet, be busy in your work, get involved in something even at the house and think less about the disease."

P6 (Male, 23) - "After knowing that I have suffered from MDR TB, I felt like it was my own fault and used to curse myself. When your body is not able to function, you start having various thoughts in your mind. I used to think if I will be dead or alive and I am young I haven't lived my life and there is so much to do."

P2 (Male, 42) - "At times I used to feel like one day I will have to die. So I will stop the treatment, discontinue the medicine. I used to think how long can I live having medicine like this."

The fear, pain the patients deal at the beginning is familiar to other patients. Few patients mention that this type of moral support has been helpful for them and the patients share their problems which also creates a strong bonding at the hostel.

Male, 33, “In the beginning of the treatment many negative thoughts come in our mind as the course of medicine is too long. We know what the patient is feeling when they first come to the hostel, so we talk to them. We tell them that life is very important and there are many things to achieve, once you begin the treatment you will be fine. They share their physical problems as well and I tell them that will stop when your body gets used to the medicine and there is nothing to be scared of.”

Awareness about the disease

The level of awareness among the public regarding TB was not uniform. Many had no idea what the disease was and those who knew about it had understood TB in their own ways. Some heard about it in the community, some from the health facilities and some from the course books. **Although aware about TB, many patients learned about MDR TB and XDR TB only after they suffered from the disease. Many patients whose family members had already suffered from TB also didn't know the disease well.**

P3 (Female, 33) - “I knew about TB but had no idea it can be this big. I always felt that the disease will be cured in six months. When the doctor said I suffered from MDR TB and then after two months XDR TB, I had no idea that these diseases existed.”

P6 (Male, 23) - “Even though my father lost his life before 6 years due to TB, I had no idea about the disease. I learned about it only after I suffered from it.”

Patients had various thoughts when they suffered from TB twice. Although they knew about the general TB, they were new to the MDR TB. Despite being told by the Dots in-charge, only a few of them practiced the prevention measures at their home

P1 (Male, 33) - “When I suffered from TB I didn't know much. When I suffered with the same disease (MDR TB) 8 months later, I became worried. Then everyone suggested me it is a communicable disease, I have to wear a mask and have medicine. I think I suffered from the disease because of my own carelessness, I became very focused in my work and it happened again and now I am here having medicine for 20 months.”

Family member, “When my husband suffered from MDR TB, I tried to adopt all the preventive measures as suggested by the doctor. Even my kids stayed away from their father as they knew the disease is communicable.”

As informed by the patients, awareness regarding the disease was a major concern to them. **Many relationships with my friends and relatives were broken due to misconceptions about TB.** The uninformed public have created an unfriendly environment for the patients and they focused on raising awareness about the disease

P4 (Male, 33), “I didn’t tell many friends I suffered from TB, only few my friends in my neighbourhood knew about it. They used to ask me to go away and wear mask. I didn’t take their behaviour personally. I felt like it was the truth as I had the disease, I cannot walk freely anywhere. I feel like if my friends had understood the disease, they wouldn’t have hated me.”

P6 (Male, 23), “Education makes a very big difference in the behaviour of the people towards TB patients.”

The health workers have emphasized on the increasing number of people coming for check-up as the increase in the level of awareness among the people. The fear of the disease has decreased. **Being aware about the disease is not enough, reaching the health facility is equally important.**

HW-1, “The number of people visiting hospital for sputum test voluntarily has increased. This shows that the people are being aware about the disease and its symptoms.”

HW-2, “It is important to have the knowledge about TB. There are many people who are still unaware about the symptoms of TB and they are not able to generalize that the symptoms like cough, blood in sputum, fever might be of TB.”

Financial hardships

Most of the patients suffering from TB had a poor economic condition. The well-off patients were said to be receiving treatment from a private health facility to maintain confidentiality. For patients with poor economic background reaching the health facility for check-up was a big challenge. **Some spent all of their earnings for treatment visiting various health facilities.** Also coming to the health centre every day for taking the medicines interferes with the work timings and causes difficulty for the patients.

P4 (Male, 22) - “Even after having medicines I didn’t get better, then I came to Butwal for check-up by collecting some money. It takes minimum 12 hours to reach Butwal from my house, I came by ambulance twice which costs 10,000-12,000 rupees. Staying outside by renting a room and managing the livelihood with the money collected was very difficult.”

P3 (Female, 33) - “Even after visiting many health facilities nothing was detected, I also went to Bharatpur Cancer Hospital. I spent a large amount of money just to detect the disease.”

Many patients receiving treatment from the hostel have said that the service has helped them a lot. However, **most of the patients didn't prefer receiving treatment from the hostel as they were the sole breadwinners for the family.** They also had a fear of managing money for treatment as they cannot collect a big amount in a short time.

Male, 48, "Everything I earned was spent while I was staying outside and receiving treatment. If I wasn't brought at the hostel then I would have sold all my properties for treatment."

Male, 26, "There are 8 members in my family and the only person earning is my father. We have been managing but sometimes it is hard to manage a big amount as the earning is not uniform. I don't work outside but I engage in household work and help my mother."

Male, 42, "I never felt like doing the treatment from the hostel. The thought that what will happen to my children how my family will manage as I am the only breadwinner encouraged me to receive treatment from home. I don't have any property and sustaining in a city like this is difficult, if I stay in the hostel I will get to eat but if I work my kids will also get food."

The economic condition of some of the patients receiving treatment at hostel is said to be very bad. Some of them cannot even afford travel expense to visit their home. **When the sole breadwinner suffers from such a disease other members try to find job to support the family.**

Support from the Government

The government has been providing nutritional allowance to MDR-TB patients. At the hostel, the MDR and XDR patients are provided shelter and food as well. Although they have been provided with food some have said that they have not received enough calories. The nutritional allowance is also said to be less and enough only for few days. They have further stressed that the government should draw its attention towards the situation and do what they can. The patients receiving treatment outside the hostel are concerned how they will manage in the days ahead. They have similar opinion regarding the allowance. For them most of the allowance is spent on transport to get to the DOTS facility.

P1 (Male, 33) - "The government should draw its attention towards our situation; we stay away from home for almost two years for treatment. The nutritional allowance is not enough. The price of fruits have gone very high banana is 80/90 Rs per kilo, apple 150 and pomegranate 200/250; how can the allowance be enough? If the government can increase the allowance it might be enough. Sometimes we do not receive the money on time, it is very difficult for those who don't have money, how will they manage? There is more that needs to be done to improve the hostel. It needs lots of cleaning, the building is old and whenever a vehicle passes nearby the building shakes. We get scared thinking it's an earthquake. The vehicles moving in the highway creates a noisy environment which irritates us most of the time."

The DOTS In-charges have also expressed their concerns about the need to have certain incentives/allowances for being involved in treating hazardous diseases like MDR TB that can easily be spread from one person to another.

HW-1, “The government has not provided any facility for people working on TB. We have repeatedly pointed out the facilities we need. For now we need hazard allowance, health insurance and TB test facility in every six months. We need the facilities but we know the scenario there is no situation we can fight for it but if provided we will be motivated.”

HW-3, “When a soldier dies, the government declares him as a martyr and provides economic support to the family. We are also a government worker but if we suffer from MDR TB at the time we retire we don’t receive any support. The government should provide facilities if we suffer from some kind of health hazard.”

HERD in MDR TB

Since supervision and patient centered care is essential for the treatment of MDR TB, HERD, in collaboration with the National Tuberculosis Programme (NTP), is implementing an implementation research titled, ‘Improving supervision and patient support approach for drug resistant TB patients in Nepal’. This is a COMDIS- HSD (a research programme consortium managed by University of Leeds, UK) uses the patient centered approach in DR-TB management to develop a comprehensive approach to supervision and patient support. It further develops clear guidelines of defining the roles and responsibilities of those involved. This study uses a working group process, involving key stakeholders including patient representatives, to develop the supervision and patient support approach.

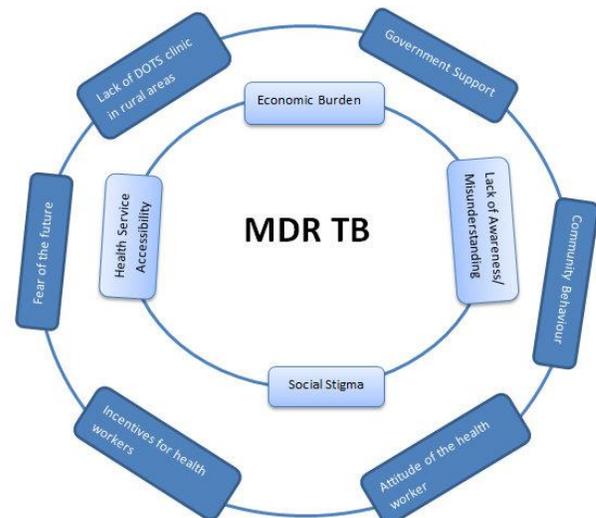
Objectives of the study

- To develop and pilot an improved supervision and patient support approach in the existing DR-TB management programme.
- To develop educational materials and support for different health care providers and patient care takers in line with this approach to supervision and patient support.
- To evaluate the effectiveness of the approach.
- To support scale-up of the proven approach across Nepal.
- To develop a generic version of supervision and patient support materials for patients and health workers.

Conclusion

TB is one of the major health problems in Nepal that can be cured if there is proper and timely diagnosis and treatment. There is growing burden of MDR and XDR TB which is a threat to the vulnerable population. Despite the efforts made by the government and other concerned agencies TB remains a major challenge. The prevalence of TB is still high and there is a need to reach the disadvantaged and vulnerable groups. There is a need to inform the public about TB and promote healthy habits. Patients should be aware about the importance of completing full course of medicine. **There is a need to conduct a survey that can provide evidence to show where we stand now.** Numerous TB patients are still said to be 'hidden' in the society. The survey will provide a solid foundation in identifying and reaching out to the unreached TB patients which will help end TB in the long run. Many patients leave their family and job behind to be treated, while most continue the treatment from home by continuing their job. Most of the patients are disturbed psychologically in the beginning, but once they are provided counselling and the treatment is started they are found more confident.

The duration of MDR TB treatment is long and the patients receiving treatment at the hostel have shown concern how they will sustain their living after leaving the hostel. The patients are weak but even though they aren't able to carry out hard tasks, they can do simple works. The patients have pointed out the need of learning skill oriented works so that they can utilise the time at the hostel and secure their future. Many people have defeated MDR TB and their life has become normal. **The happiness of having the last medicine and being informed that the disease has been cured has been labelled as 'inexpressible' by the cured patients.** The fear still exists though among the patients what if the disease reoccur and side effects doesn't cure.



The patients are found encouraging other patients to continue the medicine. They share pain and sorrow which helps the new patients to cope with the situation and realise that they are not alone. The psychosocial support provided by the health workers have encouraged many to continue the treatment. The patients are motivated to share their feelings and insecurities, which has created a strong bond. To end TB and provide various support to the MDR-TB patients, **there is a need to bring various bodies like government agencies, development partners, non-government agencies, private sector, civil society and the media together.**

References

1. National Tuberculosis Programme, Annual Reports 2005 to 2014
2. [National Tuberculosis Centre Website](#)
3. [Centers for Disease Control and Prevention Factsheets](#)