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Getting United to End TB – Celebrating World TB Day 2016

This Special Series celebrates Nepal's efforts towards tuberculosis control. Through this document, we reflect back how TB control efforts were initiated in Nepal and specifically looking back into the last ten years. We also share perspectives of the policy makers, the practitioners and the patients about how they view the TB interventions. There are emerging challenges – especially making diagnosis and treatment more accessible, cost effective and patient friendly by providing patient centered care and psychosocial support. It is high time we get united in this common endeavor towards TB elimination.

Introduction

Every year the World TB Day is marked on March 24, raising awareness about tuberculosis – cause of death for almost one and half million people every year, especially in developing countries. This year the day is being observed with a slogan, '**Unite to End TB**'. TB is one of the foremost 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.

TB Control Activities in Nepal

The government 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.



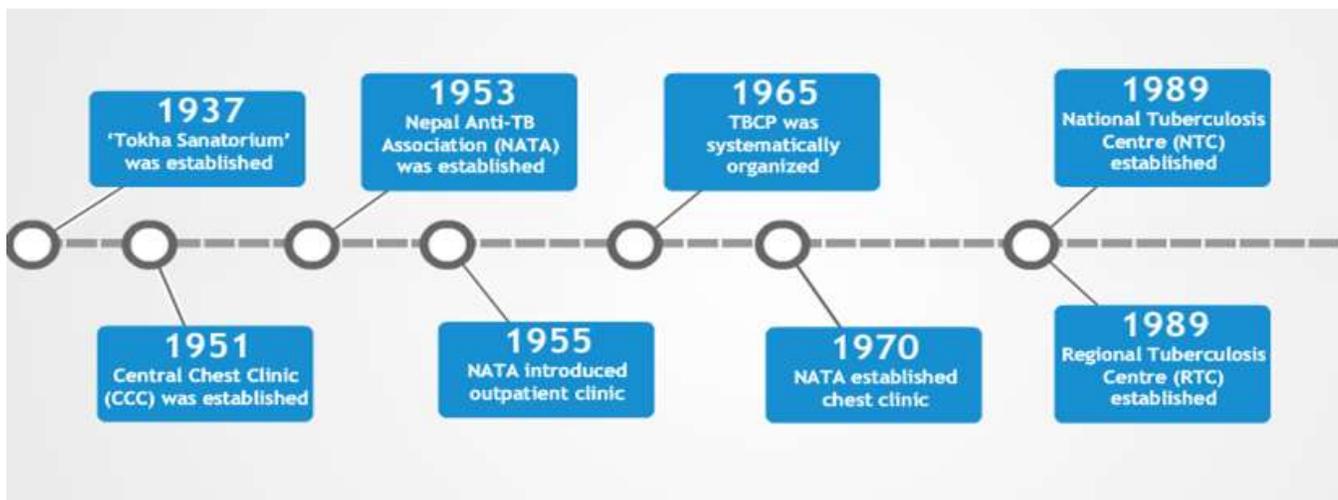
The major efforts towards TB control through NTP are:

- Free diagnostic and treatment services to all TB patients including Multi Drug Resistant (MDR) TB cases
- Passive case finding by smear microscopy through laboratory network with regular quality assurance system
- Priority given to diagnosis of sputum smear positive TB cases but diagnostic and treatment services also available for smear negative and extra-pulmonary TB cases
- Use of standardized treatment regimens (short course chemotherapy - SCC) as per NTP guidelines
- Each dose of Rifampicin to be directly observed treatment (DOT) by fully trained and regularly supervised health care workers, community members, volunteers or family members
- Use of quality assured first and second line TB drugs and availability of adequate amounts at all level of the program including provision of buffer stocks as per NTP policy
- Provision of TB HIV collaborative services at selected sites through close partnership with National HIV/AIDS Programme
- Collaboration with both public and private sector partners
- Special focus on intensive case finding high risk populations such as slum dwellers, prisoners, refugees and congregate setting such as factories, hostels and armed service personnel barracks, family members of index cases
- Close coordination and cooperation with NGOs/INGOs and external development partners
- Establishment of DOTS committee in each DOTS centre and sub-centres

TB in Nepal – Chronological Development

Tuberculosis Control Programme (TBCP) was launched by the Government of Nepal almost about four decades ago. The first step taken for TB control was initiated in 1937 with the establishment of 'Tokha

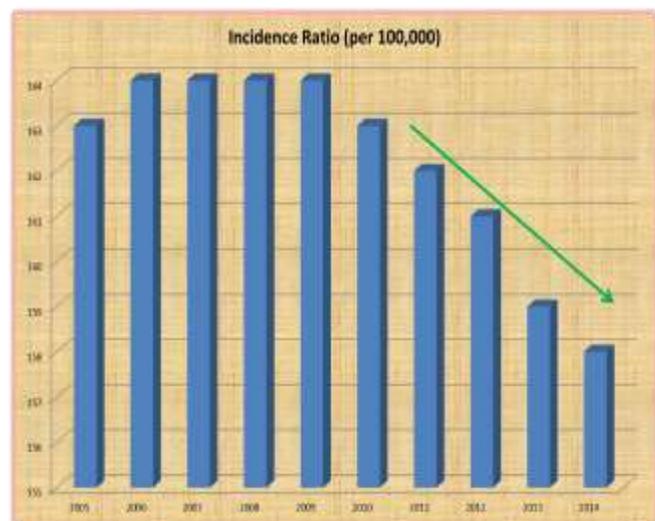
Sanatorium' situated in the north of Kathmandu city. The Central Chest Clinic (CCC) came into existence in 1951 with the facility of Diagnosis and Treatment services for the TB patients on domiciliary basis. Simultaneously, Nepal Anti-TB Association (NATA) was established in 1953 and initiated its TB Control services with opening of outpatient Clinic in 1955 and established a Chest Hospital in 1970. Similarly, in 1965, TBCP was systematically organized with tripartite agreement between the Government of Nepal, WHO and UNICEF, and since then TBCP started a nationwide TB control programme adopting preventive measures like BCG vaccination, active case findings and distribution of drugs in different integrated Health Posts. In the meantime, various national and international experts recommended that both CCC and TBCP should be amalgamated into one centre as National Tuberculosis Centre (NTC) with a view that all TB Control activities should be conducted under the leadership of National Tuberculosis Control Programme (NTP). As a result, National Tuberculosis Centre in Thimi, Bhaktapur at the central level and Regional Tuberculosis Centre (RTC) at the regional level in Pokhara were established in 1989 with the cooperation of Japan International Cooperation Agency (JICA) in order to strengthen TB control efforts in Nepal.



Major Achievements for TB Control in Nepal spanning 6 decades

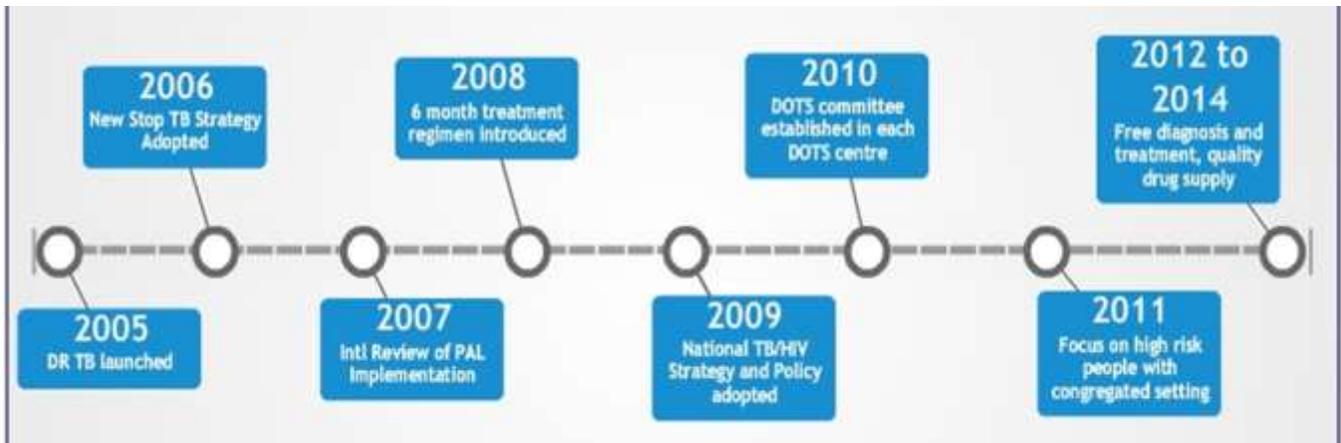
Last Ten Years (2005 – 2014) of TB in Nepal

The TB control programme has made significant inroads in the last ten years in Nepal. There has been expansion of DOTS to increasing number of treatment centres and sub centres. Global targets for case detection and treatment success rate have also been achieved. There has been a steady decline in the TB incidence ratio since 2009. The year 2014 marked innovation in TB diagnosis and treatment with the introduction of 22 GeneXpert centres. In 2014, 6.7 million USD was spent on TB programme in Nepal. Some

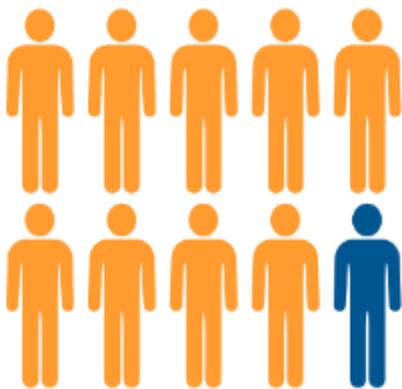


Steady decline in incidence cases since 2009

MDR and XDR cases have been reported which needs special attention. Though Childhood TB rate is minimal, if not addressed timely and appropriately, it could be a major problem in the coming years.



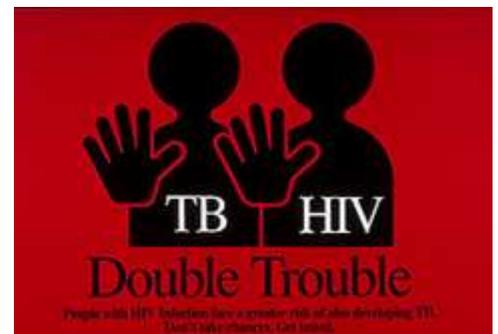
Key Milestones over 10 years of TB Control Activities in Nepal



Treatment success rate of Smear Positive Cases was 90% in 2013



2% Childhood TB cases in 2014



2.4% HIV cases among TB patients

Talking Tuberculosis: Various Perspectives

Opportunities and challenges of implementing TB programmes/interventions in Nepal is viewed differently by people in different positions and contexts. HERD team met with policy makers, practitioners and patients to understand their views about the TB programmes in Nepal.

Policy Perspectives

Dr Bikash Lamichhane, Director, National Tuberculosis Centre

The National TB Programme has prioritized MDR-TB as the number of people suffering from MDR-TB is rising. Although the government has been providing the treatment free of cost from many health posts and DOTS clinics still the number of patients enrolled in the treatment is not as it should have been. TB



brings various social, economic as well as mental problems along with it. Although we are implementing TB programmes throughout the country there is a need to improve the programme and address mental issues faced by patients- as well. NTC is committed to collaborate with government line agencies, non-government partners, development partners, private sector, civil society and media to sensitize TB agenda and work towards eliminating TB in the longer run.

Dr Bhawana Shrestha, Chief, GENETUP

We are working towards serving the people affected by TB. In the recent years, programmes like TB REACH project and GENETUP have introduced innovative approaches to dealing with TB patients. We are showing good progress but challenges still remain. Institutions like GENETUP needs to be promoted as providing targeted care especially for DR TB management cases is even more important in the current context.



Implementers' Insights

Dr Sushil Baral, Executive Chairperson, HERD



As a research organization working in the health sector for the past 12 years, TB has remained one of our priority areas. We have mainly worked as a technical support provider to the NTP in terms of bringing in our local expertise to design and implement locally appropriate interventions that cater the needs of the TB affected population. As an organization working closely at the community level, we have been advocating for patient centered care which is also reflected in our projects – providing psychosocial support, supportive supervision and reaching the unreached population through innovative technology reducing costs for diagnosis and treatment and making services accessible and affordable to public. In terms of our policy engagement, we have been contributing through policy dialogues and development of National TB Strategic Plan as well as Nepal Health Sector Strategy as a comprehensive policy documents to guide the TB interventions in the coming years and prioritizing TB within the health sector in national plans, programmes and activities. In line with this year's slogan of 'Unite to End TB', we call for a joined up effort and collaboration of all government agencies, non-government organizations, development partners, private sector, civil society and the media to share a common agenda to be united in the efforts towards ending TB.

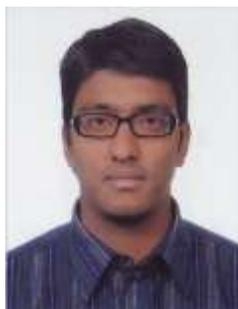
Shyam Kandel, Programme Manager, TB REACH Project

The TB REACH project has an innovative, interesting and focused approach. The participation with private sector and the cooperation with various bodies was really good which helped in bridging the gap between NTC and other partners. As the government had supported the project and was carried out with regular interaction and ownership at the central level, the district level ownership was really good that helped in smooth project implementation. We came up with some incentive packages to increase the case finding. These incentives were provided on the basis of performance



which increased the effectiveness. It is a good approach to reach vulnerable and provide them service in a cost effective way. New innovation was used and we had some challenges in the maintenance, as we didn't find any local expert in the maintenance of the machine while in district.

Prabin Shrestha, Monitoring and Evaluation Officer



We recruited more than 100 outreach workers (ORWs) and volunteers in different phases. They were oriented on conducting screening, sputum collection and recording and reporting. Each of them had to report to HERD in coordination with the respective health offices every month. Likewise, we had different reporting formats from 6 different Xpert machines. However, we had developed an internal monitoring system to track the records and reports of the ORWs and volunteers and that of Xpert machines. These reports were entered in HERD's internal system for records and reporting as appropriate. Monthly and quarterly reports were prepared and reported as required. These data were verified during field visits to the respective districts. However, the monitoring of the ORWs and volunteers was a big challenge and monitoring could not be conducted to the districts on a regular basis due to limited number of staffs.

Sudeepa Khanal, Manager – Health Systems Research

HERD is currently implementing a study on provision of psychosocial support to MDR TB patients and family members. During the designing of the study, there was already a greater realization amongst NTP and stakeholders for the need of provision of psychosocial support to MDR TB patients. This study also required development of Information Education and Communication (IEC) materials which was developed in wide consultation with NTP, its stakeholders and National Health Education Information Communication Centre (NHEICC). The study findings are shared periodically in different forums and platforms (both nationally and internationally) and the progress in the project activities are also shared in various TBCN (Tuberculosis Control Network) meetings. Since NTP was on board right from the outset of the study, and all the project activities were conducted in consultation with the partners and stakeholders, this made implementation relatively comfortable especially in terms of coordination in the implementing sites. During the study period, there have been changes in NTC leadership. The new directors were well informed about the study, its objectives and status in the beginning itself. We try to work with the government bodies like NTC for implementation of our studies for government ownership and sustainability of the programme.



Rekha Khatri, Manager – Qualitative Research



TB labs in the country are operating with minimal small space. There is infrastructure constraint, in terms of safety infection control guideline and safety guideline was not noticed. Even though the government has prioritized TB programme, laboratory staff have felt that they have not been given due importance by the programme, they have felt neglected. Now a new technology - Gene Xpert has been introduced. Still enough preparations and engagement of all programme implementers has not taken place. Engagement with those who implement the project is necessary. If the TB labs

culture facility is decentralized, then it may be easy for patients that will also help in the capacity enhancement of the peripheral staff. Now, it has been centered mostly in Kathmandu valley.

Pradip Thakali, Programme Officer

We conduct monthly visits for the MDR-TB patients. We have developed a questionnaire tool based on which we test them and enroll them in Healthy Activity Programme (HAP). We provide them psychological support so that the patients can divert their mind from the clinical complexity. All the patients are disturbed and scared we try to help them do productive things so that they become happy. HAP helps us know their problem and if the case is severe, we consult a psychiatrist. When we ask people to come talk there are very few who deny but time acts as a big barrier as they have to work. After a certain time when the rapport and a level of comfort is built with the patients, they start sharing other issues as well. It feels good when the patients appreciate when we hear about their feelings. Even though the DOTS centre provides counselling service, the patients do not open up and for those patients we become very important. This develops a kind of self-confidence among the patients they start loving their life and start hoping for a better future. Moral support is very important. When the patients find out they have MDR TB they panic, if there is no one they can talk it will be very difficult for them. They think before opting treatment as there is financial barrier and sometimes the drugs have side effect as well.



Gauri Shankar Joshi, Lab Staff: While implementing the TB REACH project, We have been appreciated and provided certificates of appreciation from many organisations like Shivam Cement of Hetauda and Nepal Handicraft Society. At some places the government officials used to travel for hours to see how we provide the service. FCHVs supported us everywhere. In all the locations we reached, there used to be people waiting for us as the notice used to be issued few days earlier. I take it as an achievement to see the flow of people coming to receive our services. This goes to show how important the project was in terms of reaching out to the unreached. The flow of people willing to do the screening was very high in Nepalgunj and Dang.

Pawan Karki, Lab Staff: We successfully provided quick and quality service to the TB patients in numerous places. In most of the places we reached, the treatment was available only for TB patients but not for MDR-TB patients, they had to travel all the way to Kathmandu for treatment. We not only provided them effective service they also received the result within few hours. The screening was also done to People living with HIV/AIDS (PLHIV) mostly kids aged 13,14 who had lost their parents. We carried out the screening of numerous PLHA at Mahendranagar, Dhangadi, Doti and Accham. Around 200 PLHA did the screening in Accham. We even reached the prisons where some positive cases were detected.



Lok Dip Dhakal, Lab Staff: Most of the places we reached had transportation problem and many people were unable to afford reaching hospitals for checkup. The flow of the patients was high in the beginning; we used to set up the camp with the support of the health facilities and district health offices. At some places, it was difficult, as we had to

explain people about the Gene Xpert and what it does. We had a tough time at Dang and Kapilbastu. For MDR TB patients as we had to do the test again it was difficult when we called them some of them used to vanish, they did not show up due to fear of social stigma. In Dang, we waited for almost two days for one MDR TB patient who did not show up. Many Indian citizens residing near the border also took the service.

Dilu Bhasyal, Outreach Worker for TB REACH project: We had lots of opportunities as well as challenges working at the Kathmandu valley but despite all the challenges we made achievements. We reached the vulnerable people at places we never expected such as prisons, factories, slum areas, camps, among others. It is hard to explain what type of sample we want and it was difficult as the patients didn't do as directed. We had to explain people as they weren't aware what Gene Xpert is. We met high-level officials they appreciated us and we even got certificates.



Maya Ghising, Outreach Worker for TB REACH project: In the beginning, we even had to deploy volunteers which was difficult. I feel that we have been contributing to society in a novel way, providing an expensive service free of cost. Now when we visit hospitals people recognize us, they are aware project and the organization. At times we also met people who were rude and ill-mannered who didn't show interest in the project. It felt good as after some time they called us themselves to conduct screening. We even collected the samples after the earthquake and during the supplies disruption. I feel that we have been able to reach such a technology to the unreached population that gives immediate and effective result in no time and helps economically as well.

Bikram Thapa, Support Staff for TB REACH project:



TB REACH programme was challenging since the beginning. I travelled to numerous districts and it was a challenge to handle the GeneXpert equipment as the parts were very delicate. We met different kinds of people, some people used to treat us like Gods serving the poor and destitute while some also criticized our work. This technology using GeneXpert helped many people especially for the daily wage workers as they had to go to work and could not afford to miss few days to get the result of their TB test. Operating the van with all the equipment was also quite a challenge especially in bumpy

and slipper roads. However, at the end of the day we used to forget all the troubles we face on our way seeing the people being happy after the screening.

Patients' Perceptions

How does it feel to be suspected of and to suffer from tuberculosis? We caught up with some patients at GENETUP and HERD and here is what they had to say. Names of the patients have been changed to maintain their privacy.



Shanti Gurung (name changed), 49 of Syaprubesi, Rasuwa used to suffer from cough and common cold most of the time. She used to live in India with her husband who used to work there as a labourer. When her health started deteriorating, she visited doctor and was given medicines and she used to feel better. The same thing would repeat repeatedly. Last year in March they returned Nepal. Her house was destroyed in the massive earthquake of April 25, 2015. After two months, she came to Kathmandu for checkup, as her kids suspected symptoms of TB. She visited many pharmacies and Teaching Hospital but the problem was not detected. Later she was taken to the NTC Bhaktapur where she learnt that she was suffering from MDR-TB. “It was disturbing as I was already going through a lot of problems. The doctor informed I have MDR-TB that did sound severe and hearing that I need to be under medication for 20 months, I panicked. The first thing

that came to my mind was I can't afford the treatment”. Seeing her economic condition, the doctor referred her to GENETUP where she received the treatment and hostel facility free of cost. Considering the unavailability of the facility at her hometown and the vulnerability of the disease to other people, she decided to complete the treatment in Kathmandu. Gurung has been receiving treatment here since last 8 months. She used to have a lot of difficulty in adjusting with the new place as none of her family members were around. She even spent days crying on the stairs thinking about how she suffered from such disease. “My brother and elder daughter had also suffered from TB both almost 15 years back. I thought I will also be fine in few months like them but 20 months is a long time. I did not know what MDR TB is and how severe it was. I used to be so scared because I was a threat to people”. She has now made friends at the hostel and shares that the hostel has changed her perspective as she has been getting a lot of support. She says, “I have not only been helped economically but psychologically too. When I first came here, I was not sure what was going to happen but with the constant support from the staff and other patients, I realized I was in safe hands. I saw numerous people suffering from the same disease that made me realize that I was not the only one. It developed a sense of self-confidence in me. Now I am confident I will stay here and receive the treatment and return home fully recovering from the disease”. Gurung considers herself as lucky that she reached the right place and says, “If I wasn't informed about the facility I don't know if I would have been alive till now”.

Hari Gurudhami (name changed), 62 of Nuwakot was suffering from dry cough since last 9 months. Initially, he thought it was seasonal flu but his condition did not get any better. His son Keshav, a farmer by profession started taking him to health facilities. He was later brought to Kathmandu and various tests were conducted for almost 6 months. In Kathmandu, Gurudhami was taken to Himal Hospital where the doctor suggested to conduct a biopsy, then he was taken to Red Cross Hospital and was under the medication for some time. The cough did not stop and he was taken to Bir Hospital. He was

given medicines for almost a month but the condition started getting severe from mid-February. Then Gurudhami was admitted at Bir Hospital on March 8. Various tests were conducted as the doctors thought it is TB or Sarcoidosis. The doctors suggested for sputum check for TB, a Montu test was conducted and to reconfirm the doctors suggested to conduct a Gene Xpert test at HERD. The test showed that Gurudhami did not have TB. The family had lost their house in the massive earthquake. Keshav shared, "It's a massive relief that my father doesn't have TB. I did not expect we will get the result so quick and free of cost. I am still worried what might have happened but now we are sure it is not TB".

Ramesh Shahi (name changed), 27 from Kohalpur of Banke was preparing to return to Korea where he had previously worked for five years. Basnet had come home for few months and had to undergo a medical check-up before returning. During the checkup at Teku Hospital the X-ray showed some abnormalities. The doctor suggested for TB test. He then did a test at GENETUP that showed negative result. However, the X-Ray results showed some abnormalities that created fear in Basnet. He was then recommended for Gene Xpert test at HERD. The result came as negative. "I was really worried when the doctor asked me to do the test. Now I am so relieved to know that I do not have TB. The result came really quick and now I can submit my medical report tomorrow".

HERD's efforts towards TB Control

Tuberculosis has remained a core service delivery area of HERD since its inception. Here is a brief description of the recent TB related projects implemented by HERD.

Reaching the Unreached through TB REACH

In collaboration with National Tuberculosis Programme (NTP), HERD initiated an innovative strategy to improve TB case detection among high risk population such as urban slum dwellers, factory workers, prisoners, refugees, monks or nuns, persons with diabetes, people living with HIV/AIDS (PLHAs) and household contacts of TB patients. Intervention was implemented through mobile camps using Gene Xpert technology in urban/municipal areas of 22 districts along with two static sites with Gene Xpert diagnostic facilities focused on TB case detection among the high-risk population. The specific objectives of the project were to identify over 2 years an additional 3136 cases of tuberculosis among urban slum populations, PLHA, prisoners, factory workers, refugees and household contacts of people living with TB; ensure the rapid diagnosis and treatment of all TB and MDR TB cases; and to continually monitor and reflect on case finding and referral strategies.

Throughout the implementation period, **145,679 people were screened and 28,574 were identified to be symptomatic.** Among the symptomatic cases, **26,447 microscopic tests** were conducted resulting in **523 microscopic positive cases.** Likewise, **9,716 Gene Xpert tests** were conducted with **746 Gene Xpert positive cases.** Thus, **1,239 cases were identified positive of which 1,195 were enrolled for treatment.** In addition to this, 404 Gene Xpert positive cases were identified among the patients who were referred from the private practitioners and private hospitals.

Ethnographic Study to Understand TB

Understanding TB: Technologies, Ethics and Programmes is a three year ethnographic study funded by Wellcome Trust and supported by University of Edinburgh. This research project aims to look at the impact of new diagnostics, the Global Fund and TB/HIV co-infection on TB control in Nepal.

Project Objectives

- Understand introduction of new diagnostics in TB and its impact in the relationship of health workers and with the patients;
- Understand the impact of the Global Fund on TB control institutions and their relations more generally in the health development sector
- Generate understanding around problems faced by people with TB/HIV co-infection and how they deal with it – individual and programme level; and develop individual/institutional capacity for qualitative research

Supervision and Patient Support Approach in Drug Resistant TB Management

Supervision and Patient Support Approach in Drug Resistant Tuberculosis Management Programme in Nepal is a psychosocial support intervention for MDR TB care in Nepal. HERD, in collaboration with the NTP and with technical and financial support from COMDIS-HSD have designed, piloted and will be evaluating an improved supervision and patient support approach aimed at DR-TB patients.

Project Objectives

- 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

Randomized Control Trial on TB – Tobacco Intervention

A three-year multi-country randomised control trial (RCT) study has been recently started in few districts to test the integration of inexpensive tobacco cessation strategies of proven efficacy into TB control programmes. The RCT has two arms: (a) behavioural support including placebo; and (b) behavioural support including cytosine with nicotine replacement drug to be tested. This study is implemented in Nepal, Pakistan and Bangladesh.

Media and TB

Issues related to health are still under prioritized by Nepali media and therefore media coverage on TB related issues is also low. The trait of considering TB as any 'common' disease as well as lack of adequate knowledge, awareness and understanding about the diseases has also led towards its under-coverage. There is also a tendency to focus about TB only during the week of March 24, when the World TB Day is celebrated.

Quality of reporting on health is also an issue with the journalists not having a wider lens in terms of understanding diseases like TB by looking into social and economic factors causing the disease such as unmanaged settlement, congested living and poverty. On the other hand, unhealthy lifestyle of the well to do class has also triggered rising number of TB cases in such groups. Here lies the importance of media to highlight these unaddressed and considered 'unimportant' issues. The media can play an instrumental role in highlighting people's sufferings and advocate for the right approach to address TB issues at the service delivery level. Likewise, media can also be significant in sensitising at the public level the dos and don'ts of health and lifestyle habits that decreases the possibility of TB occurrence and transmission.

Conclusion

TB is one of the major health problems in Nepal that can be cured if there is proper and timely diagnosis and treatment. Despite the efforts made by the government and other concerned bodies towards TB control, its prevalence is still high. Challenges exist in terms of reaching out to the disadvantaged and vulnerable groups of people. Capacity of the health institutions and the health workers along with the lack of clear policy guidelines and frameworks has made TB diagnosis and treatment more difficult.

Apart from the reactive response to tackle TB once it occurs, there is a dire need for proactive effort to inform the public about TB and promote healthy diet and proper lifestyle. Smoking has to be discouraged. Patients should realize the importance of taking full course of medicine. People infected with TB should be oriented about how they can prevent others from getting TB. In this uniform advent to get united to end TB, all the concerned bodies such as government agencies, development partners, non-government agencies, private sector, civil society and the media should come forward and work in close collaboration with a combined effort for TB elimination a reality in near future.

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