

Tuberculosis Prevention and Treatment among Migrant Workers
A Case Study of Rights Based Intervention in Nasik, Maharashtra, India

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ABSTRACT

Migrants are approximately 6 times more likely to have tuberculosis (TB) than the general population. Since migration, whether temporary or permanent, contributes to nearly one fourth of default TB cases, strategies are required to overcome this. Migrants who are living with the disease are often neglected and excluded from work by the employers because of low productivity and find them to be a liability for the organization. In order to better comprehend the situation of migrant workers in India, Public Health Foundation of India (PHFI) in collaboration with a NGO, Disha Foundation, supported by Indian Council of Medical Research (ICMR) had implemented an intervention study on Migration, Poverty and Access to health care. The study was focussed on understanding health status and health care access of internal mobile migrant workers in Nasik city engaged in construction, agriculture and informal economy. The study showed that the poor living conditions of the migrants, along with absence of specific targeted TB prevention and control strategies had left a large number of TB cases unidentified and undetected. Other barriers created stigma against the migrants like language, social exclusion, fear, lack of awareness of the informed choices, low health-related spending capacity lead to delay in the screening of the disease.

Based on above findings of formative phase, an intervention was developed to address tuberculosis among migrants. The intervention was mainly focused on promoting human rights of migrants for improved access to tuberculosis services. Key principles used for promoting human rights of migrants were non-discrimination, participation, accountability, empowerment, linkages to rights and sustainability. To summarize, the main objective of the intervention was achieved to an extent. Migrants are made aware on TB and related services, empowered by providing informed choices for screening and treatment, and making Revised National Tuberculosis Control Program (RNTCP)

more migrant friendly. Active participation of migrant employers was also ensured to make TB services more accessible at workplace. Migrant's locations under intervention were enlisted in the RNTCP's action plan, and RNTCP officials visited these locations on regular basis. On the other hand the migrants became aware of available options and were able to access the TB services as and when required. Throughout the intervention, the project team provided continuous handholding and assistance to RNTCP, employers and migrants. At local level, sustainability of the TB services was assured as migrant's locations were added by DOTS (Direct Observation Treatment) and RNTCP for regular outreach of services. But for wider coverage and longer term sustainability, RNTCP needs to design national outreach services for migrants and similar hard to reach populations. RNTCP needs to initiate special guidelines for addressing TB among informal migrant workers, with active engagement of their employers. Due to large volume of migration, special strategies for informal migrant workers at workplace are crucial to achieve the target of TB free India.

Background

India ranks 1st worldwide for burden of tuberculosis (TB); one fourth of the worldwide incident TB cases happen in India every year (*WHO 2012*). Indian government has taken significant steps to address TB problem in India through Revised National Tuberculosis Control Program (RNTCP), yet India still bears a high incidence of TB cases. The mortality rate per 100,000 population has reduced from 38 in year 1990 to 22 in 2012 (*TB India 2014; WHO 2009; WHO 2012*).

In spite of the wide approach of TB control programme to prevent the disease, early diagnosis and treatment, its universal access among hard to reach populations like migrants is minimal or absent in India. (*Kumar P, 2005*). Migrants are 6 times more likely to have TB than the general population (*Snyder 1994, cited in WHO 2001*) According to Indian census 2011, about 98.3 million people (or 31.2% of Indian population) were reported as migrants and many more are spending their life as undocumented migrants (*Census 2011*) since there are no registration policies available for migrants. Major migration categories are for work/employment (14.4 million, 14.7%), business (1.1 million, 1.2%), education (2.9 million, 3.0%), and marriage (43.1 million, 43.8%). Migration for livelihood is growing phenomenon among poor groups in India. As per 55th round of National Sample Survey Organization, there are nearly 30 million migrant workers who migrate every year across India for livelihood (NSSO). Overall, researchers estimate that there are around 120 million migrant workers across India. (*Deshingkar 2006*)

Professional migrants like business and educational professionals have better quality of life and are comparatively at lower risk of TB in comparison to poor migrants engaged in informal economy as workers. It has been observed that TB is profoundly established in the areas where basic human rights are restricted like those living in poverty and living as undocumented migrants. Migrants are

inherently vulnerable as subjects with lack of human rights from the time they leave home to initiate their migration (Bustamante 2011). Their overcrowded living and working conditions and lack of knowledge about health and health services make migrants more vulnerable to be exposed to TB. They not only face the stigma of language barrier but also struggle for their own identity (Jaggarajamma et al. 2005). Migrants usually stay in small, cheap, dense, and unhygienic areas of the cities, where overcrowding and poor ventilation are key to TB risks. Migrants face inability to access various health and family care programmes due to their temporary residential status and due to the timings of their work. Migrants remain far from the basic facilities like education, sanitation and food security. (Borhade 2011, Jaggarajamma et al. 2005). Early diagnosis and treatment of TB for such undocumented transients is necessary. There are not enough studies done on ‘Treatment rights for TB among migrants in India’ till now. There is also no specific evidence and data available on TB incidence rate among migrants. This leads to severe underreporting of TB among migrants. To reduce these vulnerabilities of migrants and thus risk and impact of ill-health, their health and human rights protection in national health policies and legislation needs to be enhanced to diagnosis and manage migration-associated TB (WHO, 2009)

About the Intervention study

Public Health Foundation of India (PHFI) had implemented an intervention on Migration, Poverty and Access to Health Care in partnership with Disha Foundation, a local NGO specialised in labour migration and development issues. The study was supported by Indian Council of Medical Research (ICMR). The broad objective of the study was to understand the factors (individual

community/system level) affecting the migrant's access to healthcare services, it also aimed to facilitate health care access to the vulnerable sector of the society.

A survey was conducted through face-to-face interviews of 4000 migrant workers, using cluster random sampling. The questionnaire was aimed to capture descriptive statistics on the socio economic, demographic details of the migrants, health indicators and their access to government health care and government's response towards addressing their health needs. Migrant households were selected for interviews that had migrated to the current city of residence within the last 10 years, but not less than 30 days, and are engaged in informal economy as a labourer.

The study was undertaken in the **Nasik City**, one of the oldest pilgrimage cities of India stands out amongst the most vital urban communities of northern Maharashtra. Nasik has attracted substantial population from the entire nation for work opportunities. Nasik is considered as one of the rapidly growing industrial cities in Maharashtra with information technology (IT) park, wine park zone, and educational hub. All these factors have attracted skilled and semi-skilled migrants to Nasik for better livelihood opportunities. Nasik's population is 3,000,000 (census 2012), which comprises 20% of migrant population from within Maharashtra as well from neighboring states such as Bihar, Uttar Pradesh, Rajasthan and Madhya Pradesh, and Gujarat.

Why human rights based intervention?

To understand why right based intervention was initiated with migrants on TB, it is important to understand how their rights to access TB services are violated. Similarly their vulnerabilities, their socio-economic profile, level of access to health services, and the barriers they face while accessing these services. These details of the study population are indicated in Table 1&2.

Out of 4000 sample size, 1839 (45.9%) migrants were between the age group of 21 to 30 years. Majority of migrants 2926 (73.1%) were males. Majority of migrants 3270 (81.7%) were migrated for better livelihood and better earnings. Majority of study population were from drought prone parts of Maharashtra (63%) and other lesser developed states of India like Uttar Pradesh (UP) (10%), Bihar (5%), Madhya Pradesh (5%), Gujarat (4%), West Bengal (4%) etc. (Table 1).

On an average, daily income of migrants was less than 200 rupees (45.5%), while more than half of the migrant's income was more than 300 rupees per day (53.9%). Migrants lived in migrant camps (69%), non-notified slums (10.9%) and open spaces (10.7%). Majority of migrants (41.6%) were staying kutchha house of which only 6.6% migrants were living in their own house. Majority of them (80.4%) were in a house with single room. 1867 (46.6%) migrants practiced open air defecation, 2055 (51.3%) migrants had no drainage system where they live, (31%) lived in houses without any electrical connection although rest had metered connections, it could be mainly possible because they were residing in the migrant camps, which had basic amenities provided by their employer. 3425 (85.6%) migrants reported that they didn't have ration card while 3270 (81.7%) didn't have voter ID as well. With respect to knowledge 2201 (55%) migrants came to know about the happenings in city via neighbors, 1155 (28.9%) possessed TV and 537 (13.4%) of migrants possessed radio. Large numbers of migrants were employed in unorganized sector like construction

site, stone quarry, agriculture, and furniture shops. Mostly migrants were semiskilled and unskilled labourers (Table 1).

Only 7% migrants reported that they use government health services during their illness, nearly 93% migrants used private health care. Migrants had reported number of barriers to access the health services/programmes; 21% reported their migration status as a barrier. Nearly 14 % of migrants mentioned timing of their work preventing them from visiting health facilities at government sectors as it affects their daily wages, while 48% reported long distance of health facility from their workplace as a barrier. Almost 11% reported language barrier as an important hindrance to access health care as most of them were from out of Maharashtra state (Table 2).

Based on the findings of the study TB emerged as a priority area of intervention due to few factors that put migrant's basic human rights at issue to access TB related services. First, due to their low literacy level and migration status, they had very limited awareness about TB including its symptoms, screening and treatment. Second, their employers did not allowed them to visit health facilities during work hours, neither they allowed health facility workers to enter their sites for TB screening and treatment. Third, the health facility itself was missing migrant specific TB awareness, screening and treatment strategies. The RNTCP officials did not cover migrants in their ongoing programs due to their pre-determined geographical areas and population. Hence there was also felt need to sensitize these services providers for inclusion of migrants in the health programs.

To reduce these vulnerabilities, and thus risk and impact of ill-health and human rights protection, need of human rights approach to the address TB issues among migrants was sensed by the project staff from these findings.

Intervention Design on Human Rights Based Approach

The intervention was carried out at 8 construction sites (including 6 ongoing construction sites, and 2 stone quarries) and 2 furniture factories, so that all migrants remain targeted in the selected sites for intervention. Nearly 5000 migrants participated in the intervention.

With reference to WHO's framework on TB and human rights of migrants (WHO 2001), human rights approach was adopted in alignment with the WHA resolution 61.17 on the Health of Migrants (WHO 2008). The project focused on the underlying social determinants of TB such as poor work and living conditions of study population. Human rights standards and principles derived from international human rights instrument were referred during the process and outcomes of intervention and advocacy with government health system (Harvard 2013). The key principles that guided the intervention are described below and are depicted in Figure 1.

1. Non-discrimination

Intervention was focused on the most vulnerable migrant population. Efforts were made to reduce their vulnerabilities by increasing their awareness on TB services, empowerment to access the TB services, and making these services more accessible for migrants by direct involvement of their employers and government service providers. Special efforts were also made with their employer to improve work and living conditions in migrant's camps.

2. Linkages to rights

The project promoted the human rights of migrants to access TB services, in line with right to health,

and WHA resolution 61.17 (2008) on the Health of Migrants, and international human rights instruments for greater impact on policy and practice specifically to promote migrant specific TB services.

3. Participation: Inclusive partnership Building

The intervention involved diverse and inclusive representation of all stakeholders from migrants and host communities. Inclusive partnership with government and non-government stakeholders, NGOs for providing primary health care services and referral system was formed. For awareness generation, project tied up with Indian Red Cross Society, as well local medical colleges. These agencies made significant contribution to conduct regular awareness programs on TB at worksites of study population. DOTS was important partners for early diagnosis and screening of TB. They initiated onsite screening camps at migrants' locations.

4. Community empowerment to access TB services

Community mobilization was done via community meetings with migrants and their employers, awareness and knowledge generation, and identification of volunteers. **Awareness & Knowledge Generation** were designed and implemented in consultation with the respective experts, addressing the needs & demands of the community with a focus on TB. Community was informed about the symptoms of TB and its impact on health, care to be taken, screening and referral services for treatment, procedures and provisions at the government health system for medical aid. The awareness programmes were conducted in collaboration of DOTS, and local NGO Disha Foundation. Health check-up camps were organized at worksites. Regular feedbacks were taken to reassess the program and make changes as per the requirement of the community. Community

meetings, lectures, street plays, film shows, were used during awareness programs. As per the language need and requirement of the communities IEC material were developed in multi-languages such as Marathi, Bengali, Hindi and disseminated widely during awareness programs, and community festivals such as Durga puja, Ganapati festival, Independence Day etc. The number of awareness programs conducted, screenings and referrals for treatment during the intervention period are depicted in Table 3.

Community level leadership development

Active community members were identified among migrants and their employers as key community leaders on the basis of their interest, leadership qualities and acceptance in their community as a leader. Training was provided to these peers for creating awareness on TB, minimizing stigma around TB patient, and facilitating access to TB screening and treatment to their fellow community members. 35 such leaders were selected and trained among migrants during the project period.

5. Ensuring accountability of government health providers and employers of migrants

5.1. Advocacy for accountability of government TB service providers: Comprehensive advocacy was carried out with Government and Non-Government stakeholders. Major advocacy was done with DOTs and RNTCP for Screening and treatment of migrants at workplace. The project team informed and sensitized these officials about volume of migrants in Nasik city, their vulnerabilities towards TB infection and absence of migrant specific outreach strategies for screening and treatment, and urgent need to make RNTCP more migrant friendly. As an outcome of sustained advocacy efforts, DOTs started inviting the project team for TB program planning meetings. List of migrant's locations was provided to DOTs by project team, special outreach strategies were developed jointly for awareness, screening and referrals for treatment. DOTs agreed to tap migrant

sites for screening of TB, and these sites were included in their monthly planning of outreach and screening camps. The project team facilitated visits of DOTs to migrants' sites for screening. Sputum test were done on the intervention sites and suspected cases were instantly referred for treatment. In initial few visits at construction sites, it was made clear by DOTs that they may need additional human resource support for sustainability of such activities, which was not available within their department. So it was consensually decided to train few volunteers of NGO-Disha Foundation, and also few community leaders among migrants. A formal training of screening of TB was provided by DOTs to these leaders. These leaders continued to arrange screening camps at migrant's sites. The screening kits were provided by DOTs, and after screening, the kit used to be send to DOTs for further investigations. If a patient was positive, treatment was started immediately by RNTCP.

5.2. Development of Referral Services

Project developed referral services for TB treatment in consultation with RNTCP officials and various government stakeholders such as Jijamata Hospital, Indira Gandhi Rugnalaya that are Municipal Corporation hospital and Civil Hospital that belongs to the state health department. Selections of these centers were made based on the nearest distance from migrant's locations, and availability of TB treatment facility.

5.3. Advocacy with employers of migrants

Advocacy efforts were crucial with the employers of migrants. The project focused on the underlying social determinants of TB such as poor work and living conditions of study population. Special efforts were made to sensitize the employers of the migrants to improve the living and work

conditions, generally employers do not allow NGOs/government officials to enter into their construction premises. Rigorous advocacy efforts were made for awareness programs on TB and screening of patients at construction sites. Special orientations of employers were organised on risk of TB for migrant workers and need of screening. After couple of sustained programs and discussions, few employers started providing permission for both awareness and screening of patients. A special one hour recess was allocated by employers for such activities. At later stage, employers were convinced for the need of such initiatives, and they demanded regular such interventions. These employers also started providing mandatory safety measures such as masks to the workers on sites. To some extent efforts were made by employer to improve living conditions of migrants by closing open drainages, construction of toilets and regular cleaning of migrants' camps.

6. Sustainability

Sustainable results and sustained change are ensured at local level by enabling migrant specific government TB services, empowerment of migrants to access TB services, and active participation of employers to enable access of TB and other health services to migrants. These stakeholders had realized their roles and responsibilities and have dedicated their resources to sustain these efforts in future. Especially RNTCP program has at least for Nasik city has added migrant's locations in their official coverage areas, and institutionalized the enabled access to TB services for migrants.

How intervention promoted rights of migrants for TB services?

The study was focused on understanding health care access of internal mobile migrant population, and response of government providers to migrants' health needs in Nasik city. There were no

specific questions in questionnaire on TB awareness or treatment part. The important limitation of this study is lack of pre and post intervention data on the knowledge attitude and practices (KAP) among migrants about TB. Hence further research should be focused to explore KAP among migrants on TB and impact of such interventions. Similar research is required to build migrant specific data on TB incidence, early diagnosis and its impact on treatment.

With this limitation, the intervention was purely designed based on the qualitative and quantitative data on poor living and work conditions which makes migrants vulnerable to TB infection, and absence of specific targeted TB prevention and control strategies that may have left large number of TB cases unidentified and undetected. The intervention was mainly focused on promoting human rights of migrant to access TB services. Key principles used for promoting human rights of migrants were non-discrimination, participation, accountability, empowerment, linkages to rights and sustainability. To summarize the whole intervention, the main objective of the intervention was achieved to some extent. Migrants are made aware on TB and related services, empowered by providing informed choices for screening and treatment, and making RNTCP program more migrant friendly. Active participation of migrant employers was also ensured to make TB services more accessible at workplace. Few employers considered improving living and work conditions of migrants. Migrant's locations under intervention are enlisted in the RNTCP's action plan now, and RNTCP officials visit these locations on regular basis. On the other hand the migrants are aware of available options and able to access the TB services as and when required. But project team provided continuous handholding and assistance to RNTCP, employers and migrants during this process. At local level, sustainability of the TB services is assured as migrant's locations are added by DOTS and RNTCP for the outreach of their services. But for wider coverage and longer-term sustainability, RNTCP needs to design national outreach services and guidelines for migrants and

similar hard to reach populations, with active engagement of their employers for successful implementation. Due to large volume of migrants in informal sector, designing of workplace interventions on TB prevention and treatment is crucial to achieve target of TB free India.

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Figure 1: Intervention Strategies adapted from principles of human rights approach



