

## **Tuberculosis in India: A need of Public Awareness & Education**

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### **Abstract**

This paper follows up an unexpected findings from the exploratory survey that identifies lack of awareness, poverty and social taboo are the most important tuberculosis risk factors. It reports perception of patients, doctors, and municipal authorities about dealing with the disease from various point of view. The study covers various socio economic angles which aggravates the spread of the disease among poor people. Views were taken from the patients, doctors and DOT (Directly Observed Treatment) providers. Some case studies have also mentioned which were found meaningful during interview of the respondents.

**Keywords:** *Awareness, education, poverty, ignorance, infectious, slums*

## **1. INTRODUCTION**

“India is the highest TB burden country globally, accounting for one fifth of the global incidence and 2/3rd of the cases in south East Asia. Nearly 40% of the Indian population is infected with the TB bacillus”(TB India 2009).According to WHO,” the four countries that had the largest number of estimated cases of MDR-TB(Multi-drug resistant tuberculosis) in absolute numbers during 2008 were China (100000) India (99,000) Russia (38,000) and South Africa” (13,000) (Sinha Kounteya 2012). India has introduced the Revised National Tuberculosis Containment Program (RNTCP) in mid 1990s for the prevention, containment and cure of TB infections in the country through WHO endorsed DOTS strategy. “In 1999 RNTCP spread to all over Mumbai also. Currently there are 24 treatment units, One TB Hospital, 501 DOT centres, 38 NGOs and 2829 private practioners under this programme.”(Mumbai Human Development Report 2009)

“TB has traditionally been seen as a poor man’s disease, but in or congested city like Mumbai, this is no longer true. There are no studies to establish that there is an economic divide in the TB patient pool”.(Masand Pratibha 2012) “Mumbai has been in or state of panic, the panic stems from the idea that we are facing a new kind of bacteria and the possibility that it may spread among a large section of people in the city”. (Krishna R 2012) “Considering that we live in a country where most people are low on personal hygiene and the rampant coughing, sneezing, spitting promptly spreads the air borne bacilli, each one of us is at some point in our lives exposed to the TB bacilli. In most cases, the infection remains latent and as symptomatic, however, one in every 12 cases progresses to an active condition depending on how weak the immune system is”. (Pal Rito 2012) “The annual case defection rate for TB in India is 156 per Lakh. In Mumbai, this number is 213. Annually 30,000 new TB cases are registered with the BMC (Brihan Mumbai Municipal corporation) (BogaDilnaz 2012) “BMC has 28,000 plus listed patients. Thousands more seek private sector treatment.” (Iyer Malathy 2012) No program for TB control can be effective unless misconception and beliefs are identified and removed. A failure of countries to attempt global case detection targets remains one of the greatest obstacles to achieving global

TB control. (Rifat, Mahfuza; Rusen, ID; Mahmud, Mohammad Hasan, MBA; Nayer, Israt; Islam, Akramul; et al. 2008)

### **Research Aims**

“TB is more common among men than women, and affects mostly adults in the economically productive age groups; around two-thirds of cases are estimated to occur among people aged 15–59 years”. (WHO 2011).Lack of awareness and education is a serious social concern about spread of tuberculosis. It is associated with poverty, malnutrition and social taboo. At present there is need for more concerned efforts from municipality, health providers and public for eradication of the disease. The Municipal Corporation of Mumbai manages the DOT program for controlling and treating the tuberculosis. In spite of that there are alarming incidences of the disease.“In directly observed therapy, patients are required to take all medication in front of healthcare workers or other service providers.”(Heymann, S Jody; Sell, Randall; Brewer, Timothy F 1998)

The objective of the study was to gain better understanding of the perception, attitude, socio- demographic factors and awareness of people towards tuberculosis in Mumbai.

The first question of the research is to understand the awareness level of disease from the patients suffering from tuberculosis.

The second question is to know thoroughly the consciousness of patients regarding the prevention of the disease.

The third question is to estimate the role of DOT providers, doctors and municipal authorities towards the prevention of the disease.

The fourth question is to suggest measures for controlling tuberculosis via public-private partnership.

## **2. RESEARCH DESIGN AND METHODOLOGY**

“Underserved population residing in urban areas long recognised to be at risk for TB”. (Wolfe, Hannah, Marmor, Michael, Maslansky, Robert; Nicholas, Stuart 1995) Based on convenience the study was conducted in G/S ward of Mumbai subject to get permission from Mumbai Municipal Corporation. 14 DOT centers were granted permission to interview the patients for a month’s time during December and January 2011-12. The sanctioned DOT centers were mainly poor inhabitants from slum dominant areas which have high incidences of tuberculosis.

Each patient was personally interviewed in DOT center. After taking the oral medicine patients were requested to wait for the interview. Some details of the patients were taken from the DOT card provided to them and from the DOT center in charge. With the oral consent of patients pictures were taken. For in-depth understanding of respondent’s lifestyle the interviewer personally visited to selective patient’s houses.

The methodology of the study consists interviewing TB patient’s socio demographic characteristics (sex, age, occupation and educational status), eating habits, hygiene, attitude and awareness about the disease. The structured questionnaire was used to collect primary information. The instrument was designed to elicit extensive data of TB patients and their internal and external environments.

The questionnaire was divided into four sections. The first section focused on the profile of TB patients while second dealt with demography and third section dealt with the behaviour of patients. The last section was designed to investigate hygiene and food habits adopted by patients. Total 290 sample were collected out of which the results of the study was carried out by interviewing 276 TB patients (N1 = 276) from different DOT centres in Mumbai. 14 questionnaires were rejected. There were total 12 MDR patients found in the study. According to health ministry officials, a single MDR patients can, if left untreated, spread the disease to 15 people every year. (Sinha Kounteya 2012) There were 9,334 cases

of MDR-TB in Maharashtra, among them 2500 were found in Mumbai. (Pal Somit) In Mumbai, 7-8% of patients with TB have HIV positive status. (Roy Sumitra Deb) In our study, 13 respondents interviewed were having tuberculosis with HIV positive.

### **Limitations of the study**

Since the respondents were interviewed at the DOT centres. The questions were asked in regional language to avoid misunderstanding. “Although all the patients seemed quite at ease and willing to cooperate, it was difficult to be sure they gave honest answers.” (Bagoes 2009) The type of disease category and weight was checked by their dot card and the weighing machine available at the centres. Some centres did not have weighing machines. Many interviews were done in the presence of the family member or accompanying person. The family also provided additional information about the patient and their role in the treatment. Some patients were not open to provide frank information.

## **3. DATA ANALYSIS AND INTERPRETATION**

### ***Socio Demographic Characteristics***

A total of 276 patients were interviewed at various DOT centres in Mumbai. The survey sample contains 156 (56.52%) males and 120 (43.48%) females. Primary survey was carried out on the TB patients aged between 15 years to 85 years. The mean age of patients was 37.42 years. Most of the respondents (29%) were between age group 15-25 years followed by 25-35 years and 35-45 years contributing 28% and 19.5% of respondents respectively. The demographic variable of the TB patients are presented in Table 1.

**Table 1: Primary Survey Composition**

Particulars	Survey Sample					
	Male	Female	Total	Male (%)	Female (%)	Total (%)
<b>Sex</b>	156	120	276	56.52	43.48	100
<b>Age Group</b>						
<b>15-25</b>	37	44	81	23.72	36.67	29.35
<b>26-35</b>	46	33	77	29.50	27.50	28.62
<b>36-45</b>	35	19	89	22.44	15.83	19.57
<b>46-55</b>	19	15	28	12.18	12.50	12.32
<b>55 above</b>	19	9	3	12.18	7.50	10.14
<b>Total</b>	<b>156</b>	<b>120</b>	<b>237</b>	<b>100</b>	<b>100</b>	<b>100</b>
<b>Employment Status</b>						
<b>Self Employed / Business</b>	23	10	33	14.75	8.33	11.96
<b>Job</b>	82	23	105	52.50	19.17	38.04
<b>Unemployed</b>	51	87	138	32.70	72.75	50.00
<b>Total</b>	<b>176</b>	<b>120</b>	<b>276</b>	<b>100</b>	<b>100</b>	<b>100</b>
<b>Education</b>						
<b>Illiterate</b>	23	36	59	14.74	30.00	21.38
<b>Primary</b>	60	40	100	38.46	33.33	36.23
<b>Secondary</b>	59	31	90	37.82	25.83	32.61
<b>Graduate</b>	14	13	27	8.97	10.83	9.78
<b>Post Graduate</b>	0	0	0	0	0	0
<b>Total</b>	<b>156</b>	<b>120</b>	<b>276</b>	<b>100</b>	<b>100</b>	<b>100</b>
<b>Marital Status</b>						
<b>Single</b>	58	39	97	37.18	32.50	35.14
<b>Married</b>	97	73	170	62.18	60.83	61.59
<b>Divorced</b>	01	08	09	0.64	6.67	3.26
<b>Total</b>	<b>156</b>	<b>120</b>	<b>276</b>	<b>100</b>	<b>100</b>	<b>100</b>
<b>Residence Type</b>						
<b>Road side</b>	4	1	5	2.6	0.83	1.81
<b>Slum</b>	70	62	132	44.9	51.67	47.83
<b>Chawl</b>	54	28	82	34.6	23.33	29.71
<b>Flat</b>	28	27	55	17.9	22.50	19.93

Particulars	Survey Sample					
	Male	Female	Total	Male (%)	Female (%)	Total (%)
<b>Bungalow</b>	0	2	2	0.0	1.67	0.72
<b>Total</b>	<b>156</b>	<b>120</b>	<b>276</b>	<b>100</b>	<b>100</b>	<b>100</b>
<b>Monthly Income</b>						
<b>Below 2 K</b>	12	11	23	7.69	9.17	8.33
<b>2-5 K</b>	58	42	100	37.18	35.00	36.23
<b>5-10 K</b>	63	43	106	40.38	35.83	38.41
<b>10-15K</b>	13	18	31	8.33	15.00	11.23
<b>15 K and above</b>	10	6	16	6.41	5.00	5.80
<b>Total</b>	<b>156</b>	<b>120</b>	<b>276</b>	<b>100</b>	<b>100</b>	<b>100</b>

Source: Primary Survey

The majority of population had education up to primary level (36.23%) followed by secondary education population contributing 32.63%. Half of the TB patients are unemployed while nearly 12% are self-employed. About 80% Of the patients have income below Rs. 10,000. The large portion of survey population resides in slum (47.83%) while only 19.93% resides in flats.

From the above discussion, it is noted that poverty, exposure to unhygienic conditions and low income generating group are more susceptible to the tuberculosis disease. Table 2 highlights factors responsible for TB susceptibility.

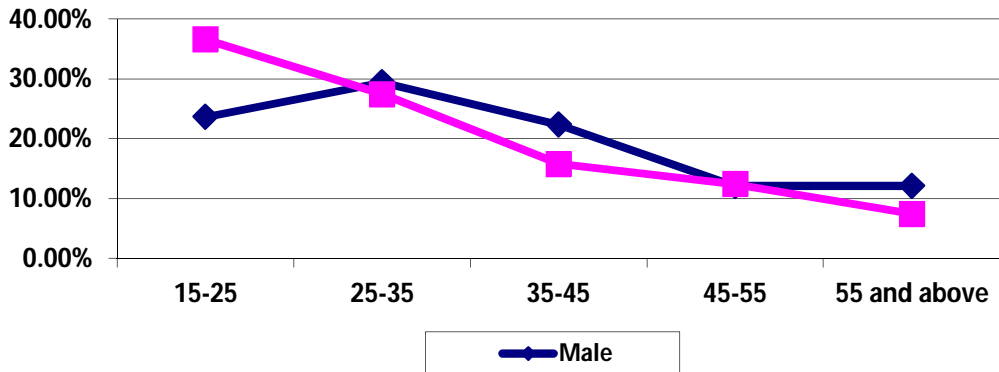
**Table 2: Factors for Tuberculosis Susceptibility**

Particulars	Observed Value (%)	Description
Poor living conditions (slums/roadside)	79	Unhygienic living and working condition increases susceptibility
Income Level (Below Rs 10,000)	80	Immunity level is compromised due to poor nutrition
Low education level (Primary education)	57	Poor knowledge can influence prevalence of TB

Source: Primary Survey

From Table 1 it is noted that occurrence of TB increases in the age group 15-35 and decreases after 35 years of age. Figure 1 gives the age wise distribution of TB patients. It is highest (29.5%) in the age group 25-35 for males while 15-25 age groups for females contributing to 36.6%.

**Figure 1: Age wise TB patients**

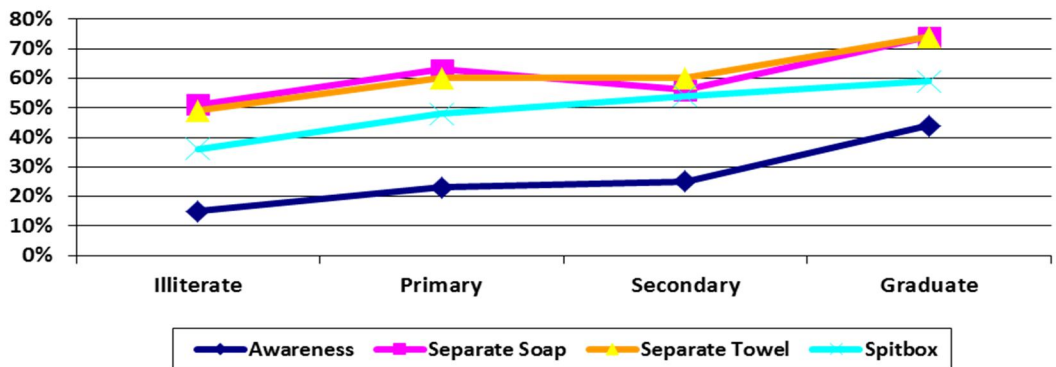


*Source: Primary Survey*

***Awareness of TB patients towards disease and its transmission***

The study was carried out in various DOT centres across Mumbai. Awareness level towards the disease TB is very low amongst the TB patients. 64% of the survey population are not aware of the treatment they are undergoing. TB patients are less concerned about the infectious nature of the disease. TB patients use common towels and soap along with the family members. About 42% and 41% of patients use common soap and towel. Only 47% of the patients use spit box for spitting while 53% of the population spit outside on road. “Unsafe sputum disposal was the predominant practice among the patients.”(KrishnadasBhattacharyya1, Rama Ram2, SP Mitra1, SK Bhattacharyya1, TK Sarkar3, U Dasgupta1 & DN Goswami 2005)



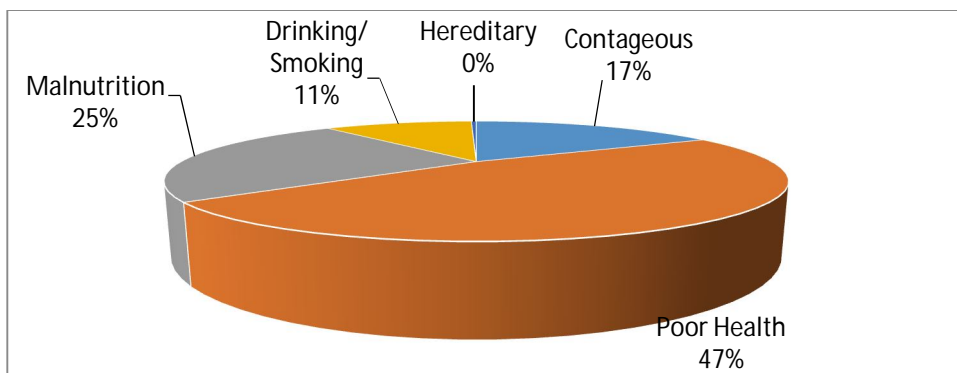
**Figure 2: TB awareness and transmission**

Source: Primary Survey

Figure 2 indicates graph between education and awareness about TB and its transmission. From the Figure 2, it is noted that, the level of knowledge about tuberculosis and its transmission has shown to have a relationship with the level of education of an individual. As education level increases, so does awareness about tuberculosis and its transmission and its curability. We found strong co-relation coefficient ( $r = 0.847$ ) between literacy level and awareness about the TB disease. A very high co-relation coefficient ( $r=0.97$ ) was found between education level and TB transmission.

***TB Disease Causes and its Treatment:*** Most of the respondents feel that poor health condition and malnutrition are the major reasons for causing TB. Poor health condition contributes 47.46% while malnutrition contributes 24.64% of the major reasons responsible causing TB. Figure 3 depicts factors responsible for causing TB.

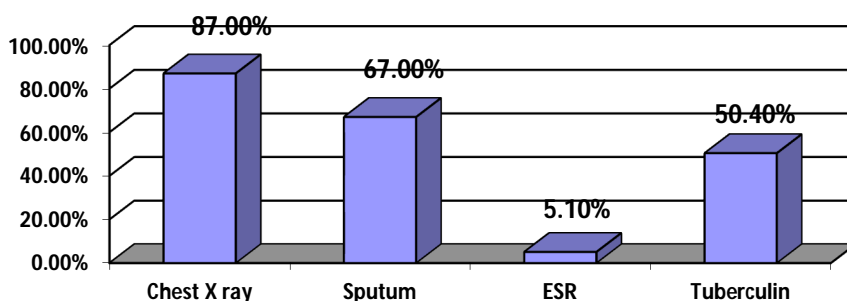
**Figure 3: Factors responsible for TB**



Source: Primary Survey

TB patients have undergone various tests including chest X ray, Sputum, ESR and tuberculin test. Most (86.96%) of the respondents have undergone chest X ray while 67.03% respondents has undergone sputum test. Very few about 5% has undergone ESR test.

**Figure 4: Test undergone**



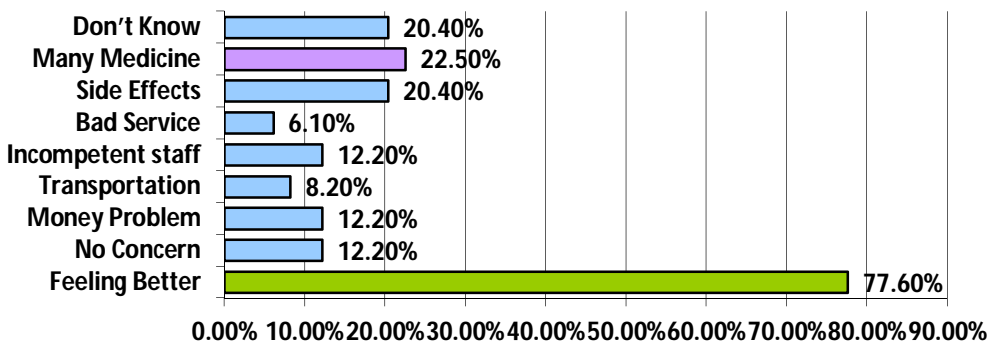
Source: Primary Survey

### ***Defaulting anti TB treatment***

When tuberculosis patients do not take their treatment regularly, they may remain infectious and develop more complications. We assessed the behaviour and characteristics of patients that took their treatment regularly and patients that did not take their treatment regularly. All 276 TB patients were asked about discontinuation of anti TB treatment. Out of 276 patients 49 patients stopped taking treatment.

About 17.75% of the patients defaulted anti TB treatment owing to better feeling after treatment, money problem and incompetence of staff. About 45% of the patients have stopped taking treatment just before six months while 30% patients stopped in last 1-3 years duration. Figure 5 depicts reasons for stop taking treatment.

**Figure 5: Reasons for defaulting anti TB treatment**



*Source: Primary Survey*

Majority that is 69.20% of the respondents have the knowledge that TB can restart after defaulting anti TB treatment. Many (60.51%) also perceive that TB cannot be cured if treatment is defaulted.

#### ***Attitudes towards TB patients***

Diagnosis of TB is associated with social stigma. Most of the respondents feel that TB patients are not accepted in the community. About 57.61% of the respondents feel that TB patients does not get support from friends and co-workers while 68.12% feels they do not get support from their employer. However majority 88.41% of the respondents get support from their family. To remove misconceptions and belief about TB, community based awareness strategies should be designed, information and education on TB must be given to the patients.

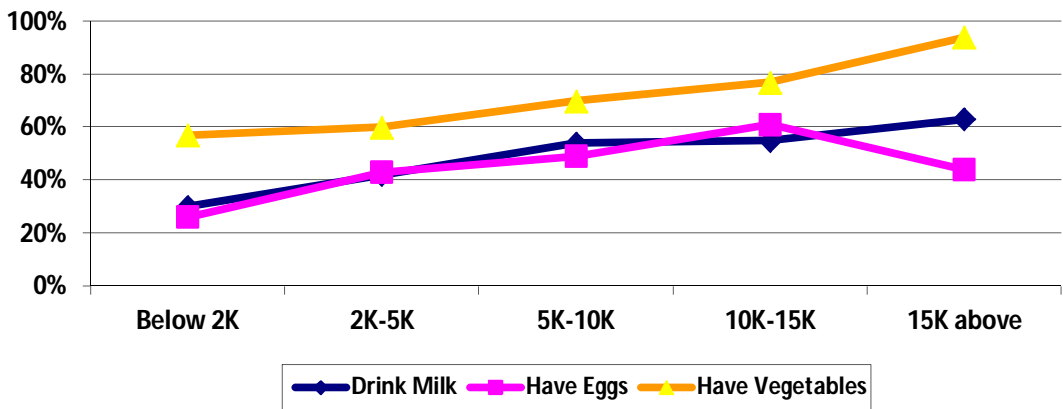
#### ***Hygiene and Food Habits***

As most of the TB patients belong to slum and low income group, the average size of their residence is 150 square feet. Majority of the patients (70%) do not

have toilet facility inside their house, they share common toilet facility with 30 to 40 persons. Most of the TB patients (40.5%) are not able to eat three times a day. It is mandatory to have eggs, milk and vegetable daily for TB patients; however 52% and 54% of the patients do not have milk and eggs daily owing to low income level.

Figure 6 indicates relationship between diet and income level of TB patients. From the Figure 2, it is noted that, intake of dietary supplements have a relationship with income of an individual. As income level increases, so does intake of dietary supplements. We found a strong co-relation coefficient ( $r=0.98$ ) between income level and intake of dietary supplements.

**Figure 6: Income level and diet**



*Source: Primary Survey*

During the course of primary survey, we made 25 contacts as indicated in Table . We analysed the data and have summarised the findings in this report. The survey was executed by one to one interaction and all interactions were documented in a designed questionnaire.

**Table 3: Primary Survey Physicians**

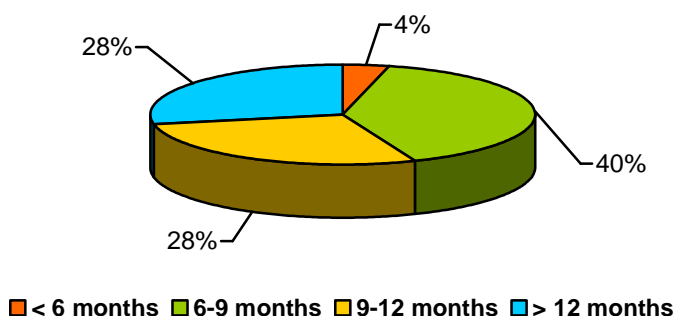
<b>Sr. No.</b>	<b>Particulars</b>	<b>Contacts</b>	<b>Percentage (%)</b>
1	DOT Centres	6	24%
2	Government Hospitals	5	20%
3	Public Health Care Centres	2	8%
4	Private Hospitals	12	48%
	<b>Total Contacts</b>	<b>25</b>	<b>100%</b>

*Source: Primary Survey*

Chest X ray, sputum, ESR and tuberculin are important diagnostic tests which are important to identify the TB patients. However only 44% of the physicians have these test facility. It is noted that all government hospitals and only 33% of private practitioners have these test facility. It has been observed that only 84% of DOT centre does not have test facility. Lack of equipment and non - availability of technicians are the major reasons cited at DOT centre to conduct these test. It was observed and confirmed from the patients that after starting the medicines LFT is not routinely done.

Most of the physicians do not have clear idea about duration of treatment regimes. When asked about duration of TB treatment, no clear duration of treatment has been observed. 40% of the physicians answered 6-9 months while 9-12 months and more than 12 months treatment regime was answered 28% of the physicians each.

**Figure7: Duration of Treatment**



*Source: Primary Survey*

Most of the physicians prescribed (40%) RIEPS drugs while 36% physicians prescribed RIE drugs. It is noted that most of the government hospitals and DOT centres prescribed RIEPS drugs while private practitioners prescribed RIE drugs. The demographic variable of the TB patients are presented in Table 4.

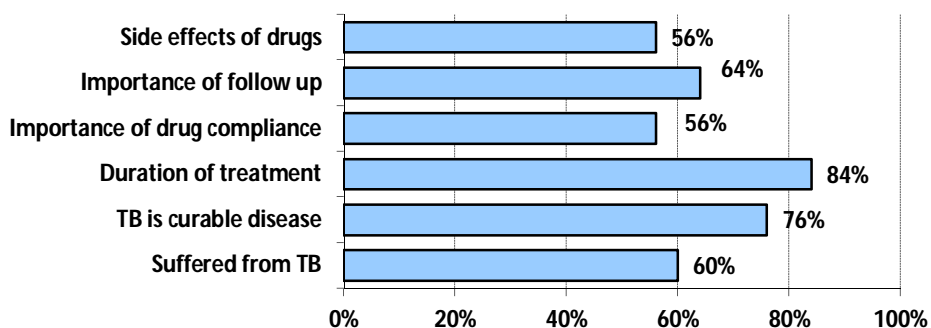
**Table 4: Anti TB Medicine**

Sr. No.	Particulars	Contacts	Percentage (%)
1	RI	3	12%
2	RIE	9	36%
3	RIEP	3	12%
4	RIEPS	10	40%
	<b>Total Contacts</b>	<b>25</b>	<b>100%</b>

*Source: Primary Survey*

R – Rifampicin, I – Isoniazid, E – Ethambutol, P – Pyrazinamide, S – Streptomycin

Physicians are good in counselling the TB patients. 84% of the physicians educate patients about duration of treatment while 76% of the physicians assure TB patients that TB is curable disease. However it is believed that patients should be educated about duration, TB is curable disease, preventive measures and importance of follow up.

**Figure 8: Counselling Practise**

*Source: Primary Survey*

When asked about follow up practise adopted by physicians, about 36% of the physicians asked their patients to come weekly for regular check-up. It is noted that 24% of the physicians adopt weekly for first two months follow practise. From Table 2, it can be concluded that 60% of physicians adopt weekly follow up practise. However, it has been observed that most of the physicians do not maintain record of TB patients which results in default in treatment.

**Table 5: Practices for follow up**

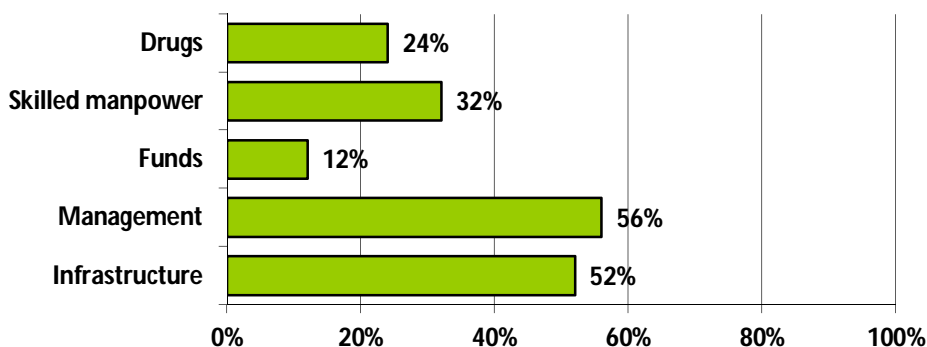
Sr. No.	Particulars	Contacts	Percentage (%)
1	Weekly	9	36%
2	Fortnightly	4	16%
3	Monthly	6	24%
4	Weekly for 1st two months then monthly	6	24%
	<b>Total Contacts</b>	<b>25</b>	<b>100%</b>

*Source: Primary Survey*

India had introduced the Revised National Tuberculosis Containment Program (RNTCP) in mid 1990s through WHO endorsed DOTS strategy. However the DOT program has not significantly reduced TB patients owing to lack of awareness and knowledge about the disease. 56% of the physicians were of the opinion that DOT program has not reduced TB cases. Infrastructure and

management of the programs are the major two reasons cited by them. Figure 5 depicts reasons for the shortfall at government hospitals and DOT centres.

**Figure 9: Shortfall at Government Hospitals / DOT Centre**



*Source: Primary Survey*

### **Status of Tuberculosis: Case Evidences**

It is noted that poverty and unhygienic conditions are more susceptible to the tuberculosis disease. We found extremely poor and helpless respondents who were not aware about the adverse consequences of the disease. 29 year old Ashwini was a pulmonary positive patient. She had three children aged 7, 3 and 1 years old. She was deserted by her husband and parents didn't support her. "He finally wanted to divorce me because of the disease" she told us. After discarding by her family she had come to destitute women's home. She was brought to the DOT centre by the shelter home officials. She was not aware about prevention of the disease.

TB patients were less concerned about the infectious nature of the disease.

Among Some worst cases found during the study was 30 year old Ganga. She was a migrant from Calcutta and worked as a prostitute. Having addicted to alcohol, pan and tobacco, her health was badly deteriorated. Extreme poverty brought her into this profession. She was pregnant. "People are advising me to abort, first trimester is going on, and I don't know what to do? She told us." She was not aware about prevention of the disease.



Forty year old housewife, Indu had extra-pulmonary tuberculosis & HIV Positive too. Her husband was also an HIV positive. Her husband was in police service and was into relationship with other women in the past. "This disease is transmitted to me from my husband but nothing can be done now" She narrated. She was aware how to prevent others from this disease.

Many times while appointing maid servants, employers don't check their health status. One such respondent was interviewed. 56 years old Prema Balmiki was pulmonary positive patient and the mother of the three children aged 30, 26 and 24. She was an illiterate and worked as a house maid. She was a tobacco addict. Her mother also suffered from this disease. She was doing all household work in employer's house and did not inform to her employers about the disease. There were eight members in her family sharing 10 x 10sq.feet room. Being aware about the infectious nature of the disease, she was using her own soap and towel.

Similar case we interviewed was 45 year old Anita who had tuberculosis and HIV AID'S positive. She was married with two children. Her husband also had tuberculosis and died. She worked in a family of eight members as a housemaid doing all household work including cooking. She knew little about prevention of disease. Her employer was unaware about her health status.

Another case we found was a patient who was removed from the job when employer came to know about her disease. 25 year old HIV positive and tuberculosis patient Gauri told "I was working as a house maid. They removed me from work. I did not take other work due to weakness. "My husband died and sister in law is also having tuberculosis. We are 7 people staying together in one room. My brothers earn very little. I suffer from loose motion and frequently need to go to toilet. I pay two rupees every time to use toilet." Gauri was not aware about prevention of the disease.

Unhygienic, low quality food and beverages supply on the road side causes spread of the disease. We interviewed Sambhaji who was 46 years old having butter milk stall. He was suffering from pulmonary tuberculosis. He used to be heavy alcoholic and tobacco user. He had two children aged 16 & 18. His brother

had tuberculosis and died. “When he is too unwell and unable to go to the stall then I prepare the buttermilk and serve the customers” told his wife.

50 years old street vendor Namdev was a pulmonary positive cat- II patient. He had two adult children. He was selling approx. 100 cups tea in a day on his road side stall. He had poor health and low immunity. Initially he was treated by private doctors but due to his careless attitude he stopped taking the medicines and the disease relapsed. He was unaware about prevention of the disease and spitting openly.

20 year old Govind, a migrant construction worker was an MDR patient and tobacco addict. He was sharing room with other construction workers. Initially he started taking treatment with private doctor, later shifted to DOT centre, as he could not afford the private treatment. His health condition and dietary intake was poor as there was no arrangement of in-house cooking. He was dependent on roadside food. He was not consuming milk, eggs & vegetables regularly. He was spitting openly.

36 years old Indrakant Jha was an HIV positive patient. He had four children. He used to be a taxi driver but due to illness he stopped working. His first marriage took place in 1995. Two years back his wife committed suicide, due to frequent fights among them over money matters. He remarried with a 28 year old girl who was staying in native place with her eight month old baby girl. She was unaware about her husband’s illness. So far no tests were undertaken for wife and any of the children. We will see when go to village” his brother narrated.

Nazma was 46 years old extra pulmonary tuberculosis patient. She had five children. Her husband was also sick and unemployed. Nazma was running a kitchen business and serving fifty people every day. Her 18 year old daughter was also suffering from pulmonary tuberculosis and helps her mother in the kitchen. “She started taking medicines from DOT centre but discontinued. She found these medicines very strong. She discontinued it and started taking treatment from the private doctor. The private doctor was charging Rs.1800 per month.

29 year old Vidya was a pulmonary MDR patient. She was having a 7 year old child. Her driver husband was alcoholic. She had seven members in the family. Her sister in law was also suffering from tuberculosis and taking private doctors treatment. Vidya was sharing common toilet with at least 40 people as she did not have toilet facility inside the house. She told “My sister in laws are very troublesome they do not allow me to eat food properly I am really fed up of my life.”

40 year Jaya was a pulmonary tuberculosis and HIV positive patient. She had only 42 kg weight. She was working in the past but now unemployed. Staying in 10’ x 10’ room with five other family members she had no toilet inside the house. She was either using municipality toilet or if it was very dirty she prefer to defecate in open sea side area. Her daughters worked as a house maid. Her breakfast was left over of the previous night, Lunch was that left over her daughters bring from owners house and dinner is dal- rice.

19 year old Gauvav was an MDR patient. His parents died and he was staying with his aunt. Till his tenth standard he was a meritorious student. Now he was working as a delivery boy. He had no addiction but his health was poor. His employer and friends were aware about his disease.

12 year old seven standard student Nikita was an MDR & HIV positive patient. After losing her HIV positive parents she was staying with her grandparents.” Due to medicines in take she suffers from mood swings”. Her grandmother told us. Nikita herself, her school mates and friend circle was unaware about the disease.

13 year old Vinaya Kamble was extra pulmonary (abdominal) Cat-1 patient. She was studying in 9<sup>th</sup> standard and stays with her grandmother who worked as a house maid. Her grandmother was tobacco user. She was staying in a five member’s family. Her mother died due tuberculosis and father abandoned her. She shares toilet with at least 30 people as there is no toilet facility inside the house. She never takes her breakfast and considered as a burden in the family.

Farukh Sheikh was a 43 year old pulmonary positive category-II tuberculosis patient. He had a meat shop. He was addicted to alcohol and tobacco. His health condition was poor. After failing the traditional treatment he started taking DOT treatment. The traditional treatment was “crushing goat liver and consumes it raw and fresh” he explained us.

35 year old Vijay was an extra pulmonary tuberculosis and HIV positive patient. He had three children. He worked as a civil contractor, staying in a 650 sq. feet house sharing a common toilet with at least 35 people. He had a family history of tuberculosis. He knew little about prevention of the disease. Except his wife no family members was aware about his disease. “He will not be accepted in the society if we tell others about his disease.” told his wife.

28 year old Anita was an MDR patient. Her body weight was 30 kg. She had two children. She used to work as house maid. Her husband was a contract worker. Due to illness she and her two children were sent to stay with the parents. There seven people were staying in a small room. Her elder sister also died due to tuberculosis. She feels breathlessness and considered as a burden on parents. “My husband and in laws don’t want anyone to know about my disease so I am sent back here” told Anita helplessly.

Kusum Gupta was 26 years old MDR patient. Her body weight was 40 kg. A house wife & mother of two children aged five and three years, She was staying in a joint family consists of 14 members. In early stage of disease for seven months she took the treatment from private doctor. Later the doctor shifted her to DOT centre. She was not aware about prevention of the disease. She was accompanied by her husband. Her condition was described by her husband only.

## **PROBLEMS OF HEALTH WORKERS**

1. No masks were given to the health workers at DOT centres. The reason was given by the health workers that authorities tell them not to use masks. “If they will use the mask it may scare the patients that they are having serious infectious disease and might not come for the treatment.”

We found health workers visiting to slum patient houses without masks and other precautions.

2. DOT centre workers receive delayed payments. They were receiving Rs.9000 per month which also was not paid regularly. In absence of regular payments and other incentives they did not find this work attractive anymore. Their Plea to get regular payments was unheard in the past meetings with authorities.
3. In absence of senior health officials visit to patient's house, there remains ignorance in understanding the actual living status of patients and finding a solution to control the spread of the disease.
4. Health workers often come across with the problems of handling patients in slums especially in red light areas. They were obstructed to go in interiors of the locality by pimps and goons for counselling the patients.
5. During monsoon when narrow lanes were full of filth, garbage, & lack of light they found it difficult to approach defaulter patients. Going to such places health workers even get exposed to water borne diseases as protective gears are not available. They find it difficult to open umbrella in narrow lanes.
6. DOT centres & Neonatal, family planning centres were functioning together in many centres.
7. No periodic scanning was conducted for the health workers as they were the most vulnerable people to get this disease.
8. DOT workers nature of job was temporary. They worked under yearly contract subject to renew every year. Some of them have spent ten years in such contractual status. They were not entitled for service benefits. Female employees were worst affected due to non-availability of maternity leaves etc. They were getting only 12 casual leaves in a year.

In case of exceeding leaves they had to go to leave without pay. Due to heavy work pressure they often fell sick.

9. Relapse of the disease was commonly observed. DOT workers find it very difficult to manage when medicines gets spoiled. There was no proper storage space provided for keeping medicines.

#### **4. DISCUSSION AND CONCLUSION**

“TB has been linked anecdotally with environmental risk factors that go hand in hand with poverty such as indoor pollution, tobacco smoke, malnutrition, overcrowded living conditions and excessive alcohol use.” (Moller, Valerie, Erstad, Ida: Zani, Dalinyebo2010). Health care, being most uncared appearance of development in slum areas. Health improvement factors are literacy, nutrition, housing, water supply, sanitation, hygiene, medical facilities, societal and economic setup. In our study it was observed that due to poor education level the respondents were unable to understand the seriousness of the issues.

The economic status of the family has a significant effect on knowledge towards care of their own and family members. The poor slum residents with high dependency ratio and poor per capita income are unable to utilize health services and therefore give path to more complicated situations.” Some populations are more vulnerable than others to infection and its effects, simply because of the relative levels of poverty and disadvantage that characterize them.”( J. Ogden; S. Rangan; M. Uplekar; J. Porter; R. Brugha; A. Zwi; D. Nyheim (1999) P. Farmer (1996) The scanty and impure water availability, inadequate sanitation facilities and lack of cleanliness makes the situation worst to increase their infection level. In extreme situation at least 300-400 people use the community toilet. The health risks of poor respondents had strong correlation with poor education, inferior quality of employment, inadequate nutrition, disgraced and strenuous environment and lack of social stability and security.

The operation of DOT program in surveyed areas depicted that some crucial problems are mounted in the achievement of better health. Due to insufficient

facilities provided in the centers, patients approach the centers, take medicines and go home or to work. Inadequate resting facilities, dietary check, drinking water and toilet facilities were not witnessed in most of the centers studied.

Our study similarly encountered difficulties in getting cooperation of practitioners working in slums. Mostly they do not have authorized allopath degree but they treat and prescribe allopathic medicines. Private practitioners just prescribed the anti-TB drugs. They neither supervise the treatment nor do follow up according to DOTS guideline as well as proper counselling of the patients regarding drug compliance. Once patient stops taking the treatment, there is no mechanism at to retrieve default cases. Therefore default rate is very high at private practitioners clinics, which ultimately increases the burden of retreating TB. (Mubashir 2009) Most of them were reluctant to interview. In absence of proper checkup devices when early stage patients are treated with them, at later stages when the disease gets aggravated and unmanageable due to complications the patients are transferred to government hospitals.

Looking closely, systematic research is needed to study the ignorance and awareness in the society towards tuberculosis. The pilot study confirmed that there is need for education at extensive scale. Unless people are informed about the worst consequences of tuberculosis, the awareness would not be created. People do hide the disease. Efficient drugs, active counseling, right advice at appropriate time and education related to environment pollution and awareness are some of the important steps. So far very less programs have been conducted for common masses.

Few corrective steps in existing set up are necessary.

Drug efficacy at the DOT center needs to be checked.

DOT workers service conditions needed to be regularized. Sufficient protective gears are must for DOT workers.

Special awareness campaign with Pharmaceutical companies support is necessary. The services of social workers could also help in health education, motivation and contact tracing of the patients. (J. Khan 2009) The state health department has asked the BMC to conduct awareness campaigns about TB, including spreading knowledge about the dangers of spitting and now TB is curable. (Pal Somita2012)

On the spot dietary provisions may help patients to continue medicines.

Proper arrangement for medicine storage is needed.

Provision of safe drinking water and toilet facility at the DOT centers would comfort the patients.

Counseling and compulsory training for slum practitioners by tuberculosis specialists is necessary to treat the patients.

Role of schools, colleges and post offices could be important to spread message of awareness.

India is the country of festivals. Many festivals are celebrated within the community. Spreading awareness during the festival may educate the masses to prevent from disease. “Interventions from the health sector specifically in social protection and urban planning have the potential to strengthen tuberculosis control”.(Hergreaves,JamesR,BocciaDelia;Evans,CarltonA,Adato,Michelle:Petticrew,Mark;2011)

Certain new provisions are also to be implemented by the government in the future. “Recently it was decided that soon drug sensitivity test will start at an important civic hospital. The identified cases of TDR-TB will be isolated in Sanatorium of Jaisinghpur, Sangli soon. The state government will give free treatment and take care of their diet. The state government has decided to send notifications to private hospitals and practitioners to report the TDR TB cases to the authorities.” (Pal Somita 2012) “The embattled civil body, already struggling to recruit staff for the TB hospital is now doing all it takes to raise the morale. It has initiated training, education and counselling sessions to begin with.” (Mishra Lata 2012)



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