Fall 2015

How Social Determinants of Health, Health-Seeking Behaviors, and Treatment Adherence Influence and Interact with Endemic Levels of Pulmonary TB and MDR-TB in Urban Rajasthan

Michelle Kagei
SIT Graduate Institute - Study Abroad

How social determinants of health, health-seeking behaviors, and treatment adherence influence and interact with endemic levels of pulmonary TB and MDR-TB in urban Rajasthan

*photo from hubpages.com

Michelle Kagei
Academic director: Dr. Azim Khan
ISP advisor: Dr. Shiv Raj Sharma, Chest and TB Hospital
SIT Study Abroad
India: Public Health, Policy Advocacy, and Community
Fall 2015

Abstract

Tuberculosis, the worlds most deadly infectious disease, remains as one of the major causes of morbidity and mortality in modern-day India. The country has the highest burden of both tuberculosis as well as multidrug-resistant tuberculosis, a more recently emerging menace. This study focuses on the social determinants of health pertaining to tuberculosis, identifying and discussing "at-risk" groups in the population of urban Rajasthan. Jaipur was chosen as the field study location because of the city's extensive levels of healthcare institutions and facilities. In order to identify common patient demographics as well as issues regarding treatment adherence, medical records and interviews were taken from patients at the Chest and TB Hospital (SMS Medical College). The data was then analyzed from both qualitative and quantitative perspectives. A wide array of healthcare professionals were also interviewed in order to gain an auxiliary understanding of patient demographics, as well as to identify factors that contribute to high endemic levels of tuberculosis and multidrug-resistant tuberculosis. The researcher hoped to further address how current government legislation and policies can take these issues into consideration in order to effectively continue the battle against tuberculosis in India.

Table of Contents

Abstract **2**

Introduction **4**
Field study location 6
Field study objectives 7
Field study methods 7

Social Determinants of Infection **8**
Sex 8
Age 9
Religion 12
Education 13
Employment 15
Caste 18

"At-risk" Groups **19**
HIV-TB co-infection 19
Migrant population 21
Seasonal migrants 21
Destination migrants 22
Smokers 23
Miners, stonecutters & silicotuberculosis 25
Diabetes & tuberculosis 26

Drug Resistance & MDR-TB **27**
Molecular pathology of resistance 27
Role of treatment adherence 28

Treatment Adherence **29**
Accessibility & availability 29
Social determinants & health-seeking behavior 30
Default patients 30
Relapse patients 33
Stigma and understanding TB 35

RNTCP & DOTS Policies **36**
MDR-TB 38
"At-risk" groups 40

Conclusion **42**
Research challenges & limitations 42
Recommendations for further study 43
Acknowledgements 44

Appendix A **46**
Appendix B **55**
Appendix C **59**
Appendix D **64**
Appendix E **67**

Bibliography **69**
Primary sources 69
Secondary sources 69

Introduction

In October 2015, the World Health Organization declared that tuberculosis passed HIV/AIDS as being the worlds most deadly infectious disease. In 2014, 1.5 million people throughout the world died from tuberculosis, while 1.2 million died from HIV/AIDS. Tuberculosis is a very large contributor to worldwide DALYs, or disability-adjusted life years, a quantitative measure of morbidity caused by disease or disability. In 2004, it caused people throughout the world to lose 34.2 million years of healthy and productive life. This burden of morbidity and mortality falls largely among a few select countries, India being the most pivotal. India continues to have the world's largest volume of tuberculosis patients as well as the fourth largest volume of drug-resistant cases. In 2014, it was estimated that the prevalence of tuberculosis was 2.5 million cases, including 71,000 cases of multidrug-resistant tuberculosis, or MDR-TB.[1]

Regarding the pathology of the disease and how it spreads, it is important to note the extremely infectious nature of tuberculosis. The disease is caused by exposure to and infection with *Mycobacterium tuberculosis,* a pathogen that spreads through the air. When an infected person coughs, sneezes, or spits and releases sputum containing the bacilli, this may infect someone else through his or her airways. About 70% of India's population is infected with the bacilli, but most are infected with a latent form, rather than active. This does not necessarily pose an immediate risk to a person's health, as most people's immune systems are able to fight off the infection. However, in those with compromised immune systems, there is a high risk of reactivation and development of the active disease. Tuberculosis infection may occur in several

[1] *2015 Global Tuberculosis Report*. Rep. no. 978 92 4 156505 9. World Health Organization, 2015. Web. 16 Nov. 2015. <http://apps.who.int/iris/bitstream/10665/191102/1/9789241565059_eng.pdf?ua=1>.

different parts of the body, though cases are most commonly pulmonary, or affecting the lungs. In extra-pulmonary cases, the bacilli may also spread to the central nervous system, the lymphatic system, the genitourinary system, the pleura, as well as bones and joints.[2] Pulmonary tuberculosis, in its drug-sensitive form, is very preventable and treatable. Due to several complex factors, the introduction of strong chemotherapy drugs has paradoxically resulted in both a larger number of cured cases, as well as the ultimate propagation of drug resistance. During recent years in India, the prevalence of MDR-TB and XDR-TB, or extensively drug-resistant tuberculosis has emerged. As some patients take the drugs long enough to extend their lives, but not long enough to fully cure the disease, the time frame in which they can infect others significantly increases. To combat these issues, the World Health Organization has recommended DOTS, or directly observed therapy, short-course. Government-registered tuberculosis patients take their treatment in front of a DOTS provider to ensure completion of the entire course. DOTS was implemented in India in 1997, with the start of the Revised National Tuberculosis Control Programme (RNTCP), India's response to high endemic levels of TB and MDR-TB.

As can be observed with most diseases and syndromes, the social characteristics pertaining to an individual tend to strongly influence his or her health outcome. In this context, this means that social determinants affect a patient's risk of primary infection, as well as the likelihood of further developing the active disease. Additionally, social determinants of health, as well as issues of accessibility and availability, are strongly tied to the health-seeking behaviors that influence the likelihood of developing further drug resistance.

---

[2] "Tuberculosis (TB)." *World Health Organization - Media Centre*. World Health Organization, Oct. 2015. Web. 16 Nov. 2015. <http://www.who.int/mediacentre/factsheets/fs104/en/>.

Field Study Location

Jaipur, Rajasthan was chosen as the field study location for several reasons. Primarily, there is a large volume of tuberculosis cases in the state. In 2011, there were 112,504 registered tuberculosis patients, which was the third highest burden of cases in India. In the same year, Rajasthan also had the third highest number of "smear-positive patients", meaning that these people tested positive for carrying *Mycobacterium tuberculosis* and had the potential to infect others through their sputum. Rajasthan is also a relevant place to study the possibility of drug resistance because of the large amount of patients who test positive for the bacilli after they have dropped out of treatment. The state had the second highest number, 7,623 cases, of "smear-positive retreatment after default patients" in 2010.[3] Patients who drop out of treatment and test positive again for the bacilli have a high risk of developing MDR-TB, which could further develop into XDR-TB.

Since the researcher hoped to investigate how an urban setting influences health outcome, being in a city was necessary. There are environmental factors unique to urban life that the researcher hoped to address, including urban crowding. In a large city of 3.5 million people, tuberculosis patients are more likely to come into close contact with others and to spread the disease. Additionally, one of the most crucial issues that the researcher hoped to study was migration from rural to urban areas, specifically the seasonal migrant population. This population consists of men who temporarily migrate to Jaipur from rural areas of Rajasthan and other nearby states in search of work.

[3] *TB India 2014 - Revised National TB Control Programme - Annual Status Report*. Rep. New Delhi: Central TB Division, Directorate General of Health Services, Ministry of Health and Family Welfare, 2014. Print.

Additionally, being both the capital of Rajasthan and one of the main healthcare hubs in northern India, there are many government facilities, medical colleges, and hospitals in Jaipur. This wide array of healthcare institutions includes statewide level facilities for the diagnosis, monitoring, and treatment of tuberculosis. Statewide medical records are kept at government facilities and there are also DOTS facilities. The researcher worked mainly at the Chest and TB Hospital (SMS Medical College) and the Directorate of Health and Family Welfare.

Field Study Objectives

The primary purpose of this research was to look at the urban population of Rajasthan and to explore how several social determinants may contribute to a high burden of tuberculosis. The researcher hoped to identify and analyze "at-risk" groups in and around Jaipur. The study also largely focused on factors that could influence the high prevalence of MDR-TB in this area. Further, another objective was to explore the factors that contribute to default, or dropping out of treatment. There was also a sub-focus on what is currently being done through legislation, like DOTS and RNTCP. The researcher hoped to explore different possibilities for how policies could better address "at-risk" groups for TB and MDR-TB as well as current issues with treatment adherence.

Field Study Methodology

The researcher conducted the project over a period of 3 weeks through several fieldwork methods, including interviews and data collection. Interviews were semi-structured, meaning that the researcher prepared a set list of questions, but added and deleted questions as was necessary. They were conducted with a wide array of persons, including TB officers, TB doctors, a TB

counselor, a lab technician, migrant and HIV/AIDS experts, as well as current patients. Through both these interviews and medical records from 174 patients, the researcher obtained demographic information as well as the diagnoses of patients at the Chest and TB Hospital. This information included each patient's age, sex, education level, religion, occupation, lifestyle behavior, any notable medical history, any social changes, and if applicable, reason for default. Upon examination of the records, patterns were identified and further analyzed. In addition to all of these primary sources, some secondary sources were also used during the study in order to gain auxiliary knowledge.

Social Determinants of Infection

The social determinants that may affect a person's likelihood of infection vary from one place to another, even within India. The following factors are very specific to Jaipur and surrounding regions of Rajasthan. The social determinants that were focused on include sex, age, religion, caste, education, and occupation. The researcher used both medical records as well as interviews with patients from the Chest and TB Hospital and found strong, weak, and non-existent correlations.

Sex

Records collected from the Chest and TB Hospital in Jaipur revealed that overall, there were more male patients than female patients. In a random sample of 50 patients collected from the TB counselor's registrar, there were 39 males and 11 females – essentially, 78% were men.[4]

[4] *Registered TB Patients; TB Counselor's Registrar*. Rep. Jaipur: Chest and TB Hospital, 2015. Print.

Similarly, in another sample of records from the general in-patient TB wards at the hospital, there were 38 male patients and 8 female patients – 83% were men.[5] Data was collected regarding MDR-TB and XDR-TB patients, however the specific statistics cannot be analyzed, as recently discharged patients were included in only the sample of male MDR-TB and XDR-TB patients. Though sex by itself, in a biological sense, may not necessarily be a strong indicator of a person's predisposed risk for developing tuberculosis, there are some points that should be considered. Primarily, mostly men are participating in behaviors and occupations that may potentially lead to being "at-risk". These behaviors, including smoking and extramarital sexual activity, and these occupations, including manual labor, stone cutting, and farming, will be discussed. In addition, solely men are participating in seasonal migration, moving away from their families for extended periods of time and putting themselves in another "at-risk" group.

Age

In most parts of the world, tuberculosis is considered a disease of old age. However, even though there certainly are numerous elderly patients, the large majority is actually middle-aged in India. As Tables 1, 2, and 3 demonstrate, the average age among TB patients was early to mid-forties. However, because there were far more males patients in the hospital, this was skewed to favor a number more representative of men. While the average age for men was 45.4 years in the records from the TB counselor's office, 48.3 years in the general TB ward, and 41.3 years in the MDR-TB and XDR-TB ward, these statistics were quite different among female patients; instead, the averages were 32.5, 33.5, and 28 years. While nearly half of male patients across the

[5] *In-patient Records, TB Wards*. Rep. Jaipur: Chest and TB Hospital, 2015. Print.

board were "middle-aged", or between the ages of 35 and 55 years old, only about one quarter of female patients were in this category.

As reported by Dr. Sajan Singh at the Chest and TB Hospital, there are multiple probable, though not proven, reasons for why the age demography differs between male and female patients. Primarily, in most households, especially in rural areas, young married women between the ages of 18 and 35 are expected to take care of everyone in the household. If a relative has tuberculosis, it is impossible for these women to separate themselves, so direct infection from a family member is quite possible. Deeply rooted in Indian culture is the practice of women prioritizing other family members' health, but neglecting to go to the doctor even if she is very sick. This leaves the possibility of a woman having a latent infection, neglecting her health and lowering her immune system's ability to fight off infection. From a clinical standpoint, women tend to have smaller chest cavities, in which symptoms tend to present themselves earlier. How much earlier is something that we do not know, at least in an absolute sense.[6]

Further addressing age demographics, Dr. Sajan Singh mentioned that there may be more middle-aged and working age male patients simply because these men are traveling outside of their household the most. Therefore, assuming there is no family contact history, they are the group that actually has the most exposure to pathogens like *Mycobacterium tuberculosis*. It is also possible that many of patients were middle-aged because these men were in their productive years of life, were the most protective of their own health, and therefore were more likely to seek treatment at a hospital. This is because being extremely sick means inability to provide for their

[6] Dr. Sagan Singh, Chest and TB Hospital. (2015, November 25th). Personal interview.

entire family. Therefore, these men may have different health-seeking behaviors from the rest of the general population.[7]

As was formerly mentioned, many TB patients are in their potentially productive years of life. The World Health Organization has stated that the disease caused India to lose an estimated 23.7 billion US dollars in 2006. Patients are often left unable to work and lose an average of 3 to 4 months' wages due to "illness-related absence from work".[8] Medical records from both the TB counselor's registrar and the wards demonstrated that about half of male patients were in their potentially productive life years ("% Working age", Tables 1, 2, & 3). Interviews conducted in the general male TB ward indicated that indeed a large amount of these men were unable to work after they contracted TB. It was found that in most cases, this was because the patient no longer had the physical strength to continue manual labor like farming. However, some patients expressed concern about infecting others, indicating another possible factor for why they did not go to their workplace.[9] In either case, being unable to work for a long amount of time may have a serious impact on a family's financial standing. It has been estimated that during leave of work, about 20% of a family's annual income may be lost.[10]

---

[7] Dr. Sajan Singh, Chest and TB Hospital.

[8] Nair, Nani, Fraser Wares, and Suva and Sahu. "Tuberculosis in the WHO South-East Asia Region." *Bulletin of WHO*. World Health Organization, Mar. 2010. Web. 24 Nov. 2015. <http://www.who.int/bulletin/volumes/88/3/09-073874/en/>.

[9] Interview with TB patients, Chest and TB Hospital. (2015, November 24th). Personal interview with translator assistance.

[10] Ahlburg, Dennis A. *The Economic Impacts of Tuberculosis*. Amsterdam: Stop TB Initiative, 2000. Print.

Table 1: *Age statistics for Appendix B patients; TB counselor's registrar*[11]

	Overall	Males	Female
Average Age (years)	42.6	45.4	32.5
% Middle-aged (35-55 years old)	28%	41%	27%
% Working age (15-45 years old)	56%	49%	82%

Table 2: *Age statistics for Appendix A patients; general TB ward*[12]

	Overall	Males	Female
Average Age (years)	46.1	48.34	35.5
% Middle-aged (35-55 years old)	44%	47%	25%
% Working age (15-45 years old)	50%	42%	88%

Table 3: *Age statistics for Appendix A patients; MDR-TB & XDR-TB ward*[13]

	Overall	Males	Female
Average Age (years)	40	41.3	28
% Middle-aged (35-55 years old)	41%	43%	25%
% Working age (15-45 years old)	72%	68%	100%

Religion

Though there was initial speculation that there may be some kind of intersection between religion and health outcome of people in this area, no data was able to support this. Out of 23 patients whose religious associations were identified in interviews at the Chest and TB Hospital,

[11] *Registered TB Patients; TB Counselor's Registrar*.

[12] *In-patient Records, TB Wards*.

[13] *In-patient Records, TB Wards*.

3 were Muslim and 20 were Hindu.[14] Considering that about 14% of the population of India is Muslim and 80% is Hindu, this was by no means surprising. In fact, if a random sample of 23 non-patients were taken from the population of Rajasthan, the religious breakdown would be almost identical. Still, there is speculation that, in some other contexts, religion may be associated with differential access to resources and therefore with differential health outcomes.

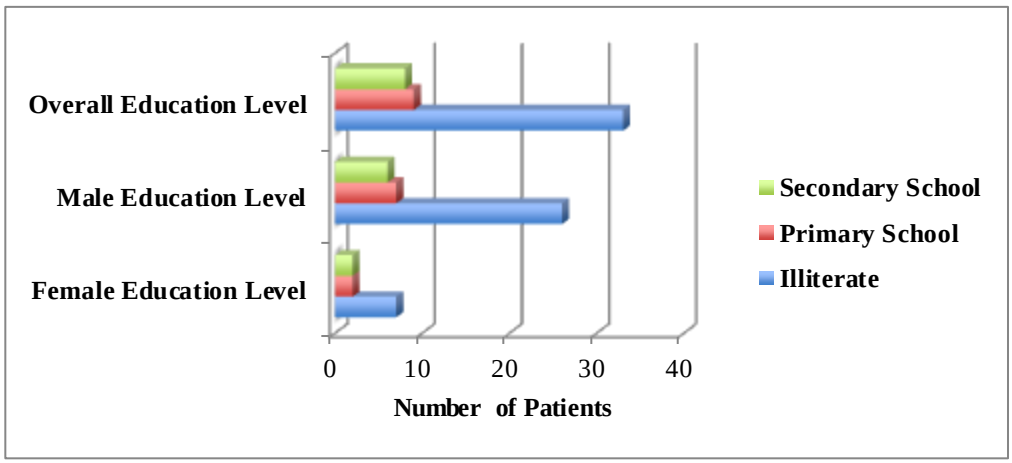
Education

Education is widely considered to be one of the most important factors in determining the health outcome and health-seeking behaviors of a person. Indeed, strong patterns emerged among the education demographics of patients at the Chest and TB Hospital. As Figure 1 demonstrates, the vast majority of tuberculosis patients were illiterate or uneducated. Across male, female, and overall population categories, about 66% of patients were illiterate and less than 20% had received either a primary or secondary school education.[15] Primary school indicates that the individual studied up to the 8th standard, while secondary school indicates the 10th standard. Higher secondary means graduation from the 12th standard.

[14] Interview with TB patients, Chest and TB Hospital.

[15] *Registered TB Patients; TB Counselor's Registrar*.

Figure 1: Highest education level attained by patients; TB counselor's registrar[16]



There are several speculated reasons for why patients tend to have lower levels of education. It is crucial to note how closely tied education is to some of the other social determinants of health, including occupation and caste. Belonging to a lower caste, having a job that involves manual labor, and having little to no education often come hand-in-hand in India. Therefore, uneducated people are also performing manual labor and farming jobs that predispose them to a higher chance of developing tuberculosis. They are also most likely to engage in risky behavior, like smoking, consuming alcohol, and visiting female sex workers. Lack of knowledge about the importance of condom use is a very important factor in determining the likelihood of becoming infected with HIV and further developing co-infection with tuberculosis. Lastly, the topics of tuberculosis, treatment adherence, and drug resistance are inherently complicated and difficult to understand with little to no education. How can someone with no science background understand the possibility of tiny bacilli in their lungs mutating and coming back as a drug-resistant form? Upon speaking to patients in the general tuberculosis ward at the Chest and TB Hospital, it became apparent that these people were told how important drug adherence was by

[16] *Registered TB Patients; TB Counselor's Registrar*.

doctors, yet had no idea why they needed to be taking these drugs for so long after they felt well.[17]

Employment

Also inherently tied to caste and level of education, employment is a very important social determinant of tuberculosis. As Figures 2 & 3 demonstrate, the majority of patients from the sample registered with the hospital's TB counselor were farmers or laborers. While they made up 76% of the sample, students only accounted for 6% and "other" occupations (i.e. tailor, food vendor, etc) accounted for 18% of the sample.[18] Likewise, in the in-patient records, it was found that manual laborers, stonecutters, and farmers accounted for 61% of patient occupations.[19]

There are a handful of justifications for why manual laborers and farmers may account for such a large proportion of the two samples. Primarily, as mentioned before, occupation was observed to be strongly associated with differential levels of education. In a sample of 29 farmers and manual laborers, 21 were illiterate (72%), 5 had received a primary school education (17%), and only 3 had received a secondary school education (11%).[20] In rural Indian culture, the occupation of farming is often passed down through generations. As boys are needed from a young age to assist their fathers and uncles with agricultural work, education is not prioritized by many families. In turn, this creates a cycle of illiteracy, from generation to generation. The lack of both general and health education influences their vulnerability to tuberculosis. Farmers and

[17] Interview with TB patients, Chest and TB Hospital.

[18] *Registered TB Patients; TB Counselor's Registrar*.

[19] *In-patient Records, TB Wards*.

[20] *Registered TB Patients; TB Counselor's Registrar*.

manual laborers exert themselves for many hours during the day, doing strenuous labor. Additionally, many construction workers and other manual laborers are also exposed to multiple physical, chemical, and biological agents, which make them vulnerable to a myriad of health issues, including respiratory problems. They work hard often in adverse weather and have poor, unsanitary living conditions.[21] Such a lifestyle absolutely can contribute to decreased immunity and increased vulnerability to infectious agents like *Mycobacterium tuberculosis*.

Most of the female patients were housewives. This was not surprising since by far, that is the most common occupation[22] among women in India. In a similar way, most of these women were illiterate; out of a sample of 10 patients who were housewives by occupation, 7 women were illiterate (70%), 2 women had received a primary education (20%), and only 1 had received a secondary education (10%).[23] Once again, there is a strong correlation between lack of education and tuberculosis. It may simply be that since most women in India are homemakers, this also accounted for the largest number of female patient occupations. Nonetheless, one alternative point needs to be considered. Intuitively, there is nothing about housekeeping that seems to expose these women to tuberculosis infection. However, Dr. Sajan Singh mentioned that housewives are expected to take care of everyone in the household, even if they are sick. Because in many cases, the living arrangement is crowded, it is difficult for these women to

---

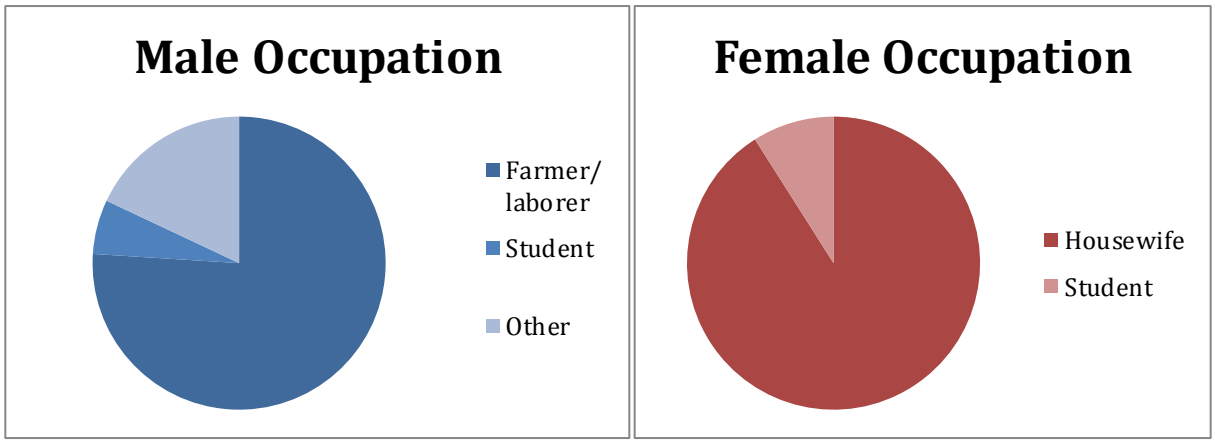
[21] Jayakrishnan, Thayer, Bina Thomas, Bhaskar Rao, and Biju George. "Occupational Health Problems of Construction Workers in India." *International Journal of Medicine and Public Health* 3.4 (2013): 225-29. *PubMed*. Web. 27 Nov. 2015. <http://www.ijmedph.org/article.asp?issn=22308598;year=2013;volume=3;issue=4;spage=225;epage=229aulast=Jaykrishnan>.

[22] Homemaking is not officially recognized as an occupation by the Ministry of Health and Family Welfare; however, in this study, it is recognized as an occupation

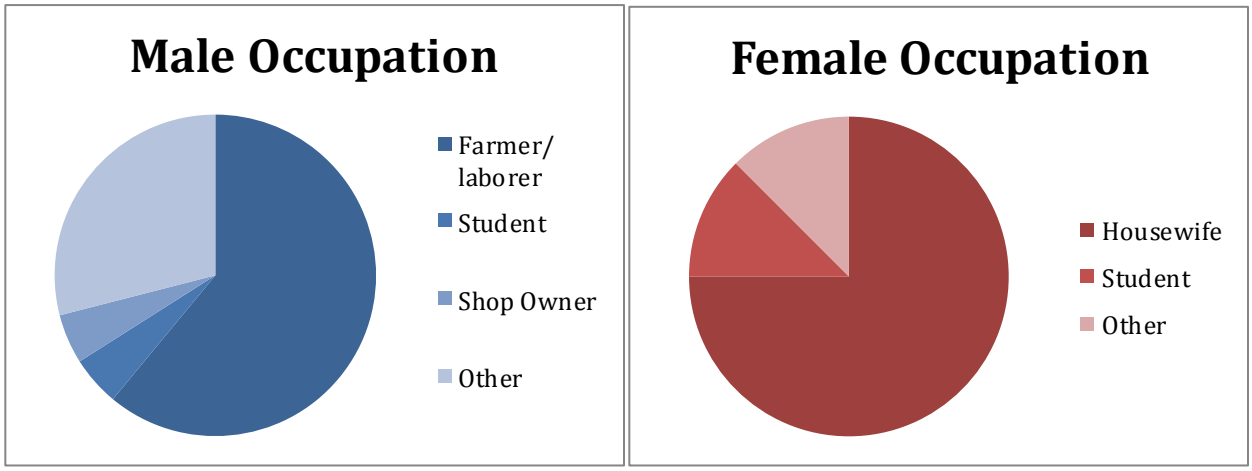
[23] *Registered TB Patients; TB Counselor's Registrar*.

separate themselves from an infected family member.[24] It is possible that the mere frequency of exposure is an important factor regarding the high prevalence of homemaking as an occupation among female patients.

Figures 2 & 3: Distribution of patient occupations**,** TB counselor's registrar, Chest and TB Hospital[25]



Figures 4 & 5: Distribution of patient occupations, TB wards, Chest and TB Hospital[26]



[24] Dr. Sagan Singh, Chest and TB Hospital.

[25] *Registered TB Patients; TB Counselor's Registrar*.

[26] *In-patient Records, TB Wards*.

Caste

Tuberculosis is often referred to as the child of poverty in India. Though the strong association between tuberculosis and poverty is very commonly known, the specific issues behind this are less obvious. People living in poverty are mostly from lower castes in India. The institutionalized and widely culturally practiced caste system has absolutely contributed to the vast inequities in health status and vulnerability to diseases like tuberculosis. Although the researcher was not able to gather specific data regarding patients' castes at the Chest and TB Hospital, it was apparent that most patients belonged to either scheduled castes (SC) or other backward castes (OBC).

One of the most important factors to consider is the environmental injustice that Indians living in poverty must face. The 2006 Demographic Health Survey for India indicated that there was a correlation between household socioeconomic status and TB determinants and status. Data from 198,754 people was used to calculate population attributable fractions for several TB risk factors. Primarily, it was found that the prevalence of self-reported TB was five times higher in the lowest quintile of socioeconomic status than the highest quintile. It was also found that among those living in poverty, the calculated possible risk factor for people with low BMIs was 34.2% and 28.5% for people living with indoor air pollution.[27] People from the lowest castes in India, oftentimes live in urban slums, which are overcrowded with poor ventilation; they face health issues because of this. Inability to afford nutritious food is also a large issue. Impoverished, malnourished individuals have decreased immunity and an increased risk of developing tuberculosis. Additionally, once a family member becomes a tuberculosis patient,

[27] Oxlade, Olivia, and Megan Murray. "Tuberculosis and Poverty: Why Are the Poor at Greater Risk in India?" *US National Library of Medicine - National Institutes of Health* (2012): n. pag. *NCBI*. Web. 30 Nov. 2015. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3501509/>.

families living in poverty must face huge economic burdens including, but not limited to, lost pay because of inability to work, travel expenses, and sometimes, out-of-pocket medical expenses.

"At-risk groups"

Globally speaking, patients who are considered to be "at-risk" for developing tuberculosis are those with compromised immune systems and/or extensive exposure to *Mycobacterium tuberculosis*. This absolutely applies to an Indian context, but there are several social factors and determinants very specific to urban Rajasthan that call for further discussion.

HIV-TB co-infected patients

The most widely discussed category of "at-risk" patients is those who have HIV/AIDS, or human immunodeficiency virus with acquired immune deficiency syndrome. As was previously mentioned, 70% of India's population is actually infected with the bacteria, however around 95% of these cases never develop into an active, culture-positive form of infection because most people's immune system can fight off the bacilli. However, people infected with HIV/AIDS are the prime example of a population with compromised immune systems; reactivation of latent bacilli is very common in these patients. Though this estimation may fluctuate, Dr. Sajan Singh mentioned that in his observations, about 40% of HIV/AIDS patients are co-infected with tuberculosis at some point during their lives.[28] At the Chest and TB Hospital, these records were

[28] Dr. Sajan Singh, Chest and TB Hospital.

kept confidential, so the researcher was unable to access information directly. However, in 2011 at the ART clinic of Pravura Hospital, Loni, a study showed that in one given time period, 17% of the HIV patients currently receiving ART were co-infected with tuberculosis.[29] This, in itself, is quite a large proportion of patients, but the fact that this is a limited period of time needs to be considered. Since tuberculosis is an opportunistic infection in HIV patients, it could happen at any time, and this statistic does not even include patients who have already had tuberculosis or who will in the future.

In addition to all of this, because ATT, anti-tuberculosis treatment and ART, anti-retroviral therapy, are both very strong sets of medication, there can be complications. The potency of one treatment regimen may be compromised or strong side effects may be experienced. Specifically, rifampicin has been observed to have adverse effects when taken at the same time as ART. Mrs. Kareena Jain, a lab technician who tests for HIV status among patients at the Chest and TB Hospital, revealed that when there are complications, the patient usually goes to the doctor to determine which medication is causing problems. The treatment is adjusted accordingly, but if either ATT or ART needs to be compromised, usually ATT is prioritized (if the patient's CD4 count > 200) because tuberculosis poses more of an immediate danger to the patient's life. However, this further complicates the situation because if a patient is unable to receive ART, this compromises their immunity and therefore their ability to fight off the tuberculosis while taking the anti-tuberculosis drugs.[30] HIV-TB co-infection is an extremely complicated and unfortunately prevalent issue in urban Rajasthan.

---

[29] Phalte, Deepak B., Girish A. Purushottam, and Jayant D. Deshpande. "Prevalence of Pulmonary Tuberculosis Among HIV Positive Patients Attending Antiretroviral Therapy Clinic." *US National Library of Medicine – National Institutes of Health* (2012): n. pag. *NCBI*. Web. 26 Nov. 2015. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3731868/>.

[30] Mrs. Kareena Jain, lab technician at Chest and TB Hospital. (2015, November 19th). Personal interview with translator assistance.

Migrant populations

The trend of migration from rural to urban areas is very important in regards to the population's health outcome. An interview with Vimal Kapoor, a migrant expert at RSACS, or Rajasthan State AIDS Control Society, shed light upon the numerous issues regarding the health of migrants in Jaipur. Primarily, there are three types of migration: rural to urban, semi-urban to semi-urban, and semi-urban to urban. Additionally, there are three categories of migrants: source migrants who are born around Jaipur and move elsewhere, destination migrants who are born far outside of the area and immigrate to Jaipur, and transitory, or seasonal migrants who move in and out of the Jaipur area during different time of the year.[31] As this research focused on the population of Jaipur and surrounding districts, only destination and seasonal migrants were addressed.

Transitory/Seasonal Migrants

Primarily, a large portion of migrants are seasonal; they spend part of the year in their native rural land, doing agricultural work, and migrate to semi-urban and urban areas like Jaipur to do work for the rest of the year. According to a migrant expert at RSACS, the jobs that these men participate in include mining, stone cutting, construction work, and other forms of manual labor.[32] The first factor that affects these migrants' health is the noxious environments that these men do exhaustive work in every day. Poor working and living conditions subject them to respiratory ailments.

---

[31] Nimal Kapoor, Migrant Expert at RSACS. (2015, November 19th). Personal interview.

[32] Nimal Kapoor, Migrant Expert at RSACS.

Further, seasonal migrants travel alone most of the time, which is a danger by itself. The migrant expert noted that for those who come from the rural pocket to an urban center like Jaipur, their lifestyle changes quite a bit. Because they make a little more money and want to celebrate, they indulge in alcohol and the sex worker industry. Being alone in the city, rather than migrating with a family, poses a much larger risk. Also, there is a strong sense of camaraderie between co-workers and men often peer pressure each other into visiting the female sex workers. Lastly, the pure volume of female sex workers available encourages more men to go to these places and risk being infected with HIV.[33] In a 2010 study by NACO, the National AIDS Control Organization, it was published that 1.3% of female sex workers were infected with HIV in Rajasthan. There were over 21,000 female sex workers in Rajasthan in 2006, which is the last known official statistic, though that number is estimated to be much higher now.[34]

Destination Migrants

Though seasonal migrants contribute to the majority of the migrant population in Rajasthan, destination migrants are also considered to be "at-risk" to an extent. This group includes those who may migrate from one rural or semi-urban area to an urban or semi-urban setting. According to Abhishek Narang, a microbiologist who focuses on HIV in migrant populations of Rajasthan, many people migrate from different states to Rajasthan; these include Tamil Nadu, Maharashtra, Uttar Pradesh, and Andhra Pradesh.[35] In addition to this, people

[33] Nimal Kapoor, Migrant Expert at RSACS.

[34] National AIDS Control Organization. *HIV Sentinel Surveillance 2010-2011: A Technical Brief.* Rep. New Delhi: Ministry of Health & Family Welfare, Government of India, 2012. Print.

[35] Abhishek Narang, microbiologist and HIV/AIDS expert at Directorate of Health and Family Welfare. (2015, November 14th). Personal interview.

emigrate from other districts within Rajasthan. The large-scale industries around Jaipur attract many migrants, both seasonal and destination.

In most cases of destination migration, whole families relocate, most often to urban slums. Upon moving, sometimes it is difficult for these people to connect with the healthcare system in their new setting. If someone was receiving treatment for tuberculosis in their home and they move, the tracking of these patients becomes a larger issue. According to Mr. Narang, it is possible to track the patient and make sure that they followed up with treatment if they moved within Rajasthan, but very difficult if they crossed state borders.[36] So, in some cases, it is completely up to the patient to make sure that there is a smooth transition from one healthcare facility to another. Theoretically, this would be very difficult if the patient were travelling for a few weeks to a month. Migrant families living in urban slums are often marginalized in urban communities and do not necessarily feel as though they can easily access healthcare facilities. From an environmental standpoint, the overcrowded, unsanitary conditions that some migrants live in subject them to high levels of exposure to the bacilli as well as impaired immunity.

Smokers

In the sample of TB, MDR-TB, and XDR-TB patients from the Chest and TB Hospital, the prevalence of smoking was measured. Among patients in the general ward, 51% of patients were smokers or ex-smokers; further, this was broken down to 60% among male patients and 12% among female patients. Quite similarly, in the MDR-TB and XDR-TB ward, overall 58% of patients had been smokers, which broke down to 62% among males and 25% among females.[37]

[36] Abhishek Narang, microbiologist and HIV/AIDS expert at Directorate of Health and Family Welfare.

[37] *In-patient Records, TB Wards*.

When compared to the prevalence of smoking in the overall population of Rajasthan, the rates among these TB patients are much higher. In 2010, a survey showed that 18.8% of the overall population of the state consisted of smokers; among men, 33.3% were smokers and among women, 5% were smokers.[38] Though it is evident that TB patients are more likely to be smokers than the general population, it is important to note that the statistic regarding the general population is limited because it does not include ex-smokers. Several studies have supported the strong correlation between smoking and susceptibility to tuberculosis. At the Himalayan Institute Hospital, Dehradun, India, 95 TB patients and 190 controls were randomly selected to assess smoking as a risk factor for tuberculosis. The odds ratio for pulmonary tuberculosis and smoking was 3.44 ($P = 0.0001$) and was 3.56 ($P = 0.0067$) for extra-pulmonary tuberculosis,[39] meaning that, indeed, there is a strong association between tuberculosis and smoking.

From a clinical standpoint, there are a few reasons for the strong association between tuberculosis and smoking. Dr. Sajan Singh has stated that smoking leads to a local loss of immunity, which increases susceptibility to active, symptomatic tuberculosis. However, it is not necessarily this local loss of immunity that is a major determinant. As was observed in numerous patients' medical records, there is a very high chance of chronic smokers developing COPD, chronic obstructive pulmonary disease. After years of suffering from COPD, a person begins to lose the clearance mechanism for mucus; this strongly impacts someone's ability to fight off

[38] Singh, Akansha, and Laishram Ladusingh. "Prevalence and Determinants of Tobacco Use in India: Evidence from Recent Global Adult Tobacco Survey Data." *NCBI*. US National Library of Medicine: National Institutes of Health, 4 Dec. 2014. Web. 25 Nov. 2015. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4256395/>.

[39] Gambhir, Harvir S., Rajeev M. Kaushik, Reshma Kaushik, and Girish Sindhwani. "Tobacco Smoking-associated Risk for Tuberculosis: A Case-control Study." *International Health* (2010): n. pag. *Oxford Journals*. Web. 25 Nov. 2015. <http://inthealth.oxfordjournals.org/content/2/3/216.abstract>.

infection with *Mycobacterium tuberculosis*.[40] Hence, a large number of patients who smoke ultimately damage their body's natural ability to protect itself from active bacilli.

Miners, stonecutters & silicotuberculosis

Mining and stone cutting are two of the largest industries in Jaipur and surrounding districts, employing millions of people. Endowed with rich land full of many minerals, Rajasthan boasts 20% of all mining lands in all of India. Though these large industries may benefit the state economically, there are horrendous environmental health consequences that are impossible to ignore. People working as miners and stonecutters are exposed to loose silica dust for 12+ hours a day, which over time, has very deleterious effects on an individual's health. Mining, stone cutting, and other forms of manual labor are often associated with silicosis, or lung fibrosis caused by inhalation of dust containing silica.

The wards of the Chest and TB Hospital frequently have cases of silicosis, most commonly seen in the form of silicotuberculosis, or silicosis paired with tuberculosis. Upon examination of medical records, it was observed that nearly every patient with silicosis also suffered from pulmonary tuberculosis. Silicotuberculosis is almost exclusively seen in patients who perform some kind of manual labor, like mining or stone cutting. In-patient records in the general male tuberculosis ward revealed that out of 33 patients, 4 had silicosis, or 12%. In stark contrast, 67% of people with a stone cutting background were diagnosed with silicosis (4 patients out of 6).[41]

---

[40] Dr. Sajan Singh.

[41] *In-patient Records, TB Wards*.

There are a few components regarding how the pathology of silicosis infection makes people so vulnerable to tuberculosis. As has been discussed, impaired immunity majorly determines who will be infected with the active disease. According to Dr. Sajan Singh, when the foreign silica dust enters someone's body, it impairs cell-mediated immunity. Most of the lymphocytes surround the silica as part of the body's immune system response. However, because the body's immune system is so focused on the silica dust as a foreign invader, this creates an opportunity for reactivation of *Mycobacterium tuberculosis*.[42] Also, there is a speculated synergistic effect between silicosis and tuberculosis, as the two diseases may complicate each other. For example, it has been hypothesized that silica particles absorb the body's iron and act as reservoirs for this iron, which bacilli depend on iron for growth. Silicoto-iron complexes are said to also possibly activate dormant tubercle bacilli.[43] Evidently, there is an important relationship between silicosis and tuberculosis.

Diabetes and tuberculosis

In recent years, a double burden of disease has emerged in India, meaning that the country bears the burden of both communicable and non-communicable disease. Alongside infectious diseases like tuberculosis and HIV, the high prevalence of diabetes is a growing issue in India. The country currently hosts over 62 million diabetics, the highest volume globally. The World Health Organization predicts that this number will grow to almost 80 million people by

[42] Dr. Sajan Singh, Chest and TB Hospital.

[43] Hazarika, Basanta, Dr. "Silicosis and Silicotuberculosis." *Department of Pulmonary Medicine, PGIMER, Chandigarh*. Web. 22 Nov. 2015. <http://www.indiachest.org/teaching_material/Silicosis%20and%20silicotuberculosis.pdf>.

2030.[44] Research has demonstrated that diabetes has been proven to reduce cell-mediated immunity, further endangered those who are exposed to the bacilli. Globally speaking, diabetes has been estimated to account for around 15% of present tuberculosis cases. In addition to increasing risk of developing tuberculosis, higher rates of relapse and eventual mortality have been associated with diabetes patients.[45] Though intuitively, there seems to be little to no relationship between infectious and non-communicable disease, the association between diabetes and tuberculosis is very important to consider in future public health efforts.

Drug Resistance & MDR-TB

Molecular pathology of resistance

Upon initial diagnosis of tuberculosis, a patient's forthcoming behavior is extremely important. This is because treatment adherence has a large effect on whether the pathogen becomes multidrug-resistant, which is officially defined as being completely resistant to the two strongest first-line drugs: isoniazid and rifampicin. Though more rare, there is also the danger of MDR-TB becoming extensively drug-resistant, or resistant to rifampicin, isoniazid, any fluoroquinolone, and at least one of three injectable second-line drugs. Though extremely rare, XDR-TB is at risk for becoming totally-resistant, in which case there is nothing a clinician can do, aside from prescribing symptomatics for the patients' own comfort.[46]

---

[44] "Country and Regional Data on Diabetes." *Diabetes Programme - WHO*. World Health Organization, 2015. Web. 29 Nov. 2015. <http://www.who.int/diabetes/facts/world_figures/en/>.

[45] "Tuberculosis and Diabetes." *Diabetes and Endocrinology*. The Lancet, 4 Sept. 2014. Web. 29 Nov. 2015. <http://www.thelancet.com/series/tuberculosis-and-diabetes>.

[46] Dr. Rajesh Meenan, Resident at Chest and TB Hospital. (2015, November 20th). Personal interview.

If a patient takes anti-tuberculosis drugs for a while, but does not completely finish the treatment regimen for any reason, there can be very serious consequences. Though the patient's symptoms may be relieved, there are still active bacilli in the patient's respiratory tract. These may have spontaneous mutations in their chromosomes that are thought to confer resistance to anti-tuberculosis drugs. For example, more than 95% of rifampicin-resistant strains are linked to mutations in an 81-base pair region of the *rpo*β gene. However, resistance to isoniazid is much more complicated, as it is controlled by several genes and loci.[47] Some bacilli that were able to survive only partial treatment may have these mutated genes that allow them to survive and proliferate, essentially creating more drug resistance.

Role of treatment adherence

Evidently, completion of the entire treatment regimen is very crucial. Those who fail to adhere to their treatment, whether this is directly due to social factors or not, have a high risk of relapse and potentially add to the growing issue of drug resistance in India. A doctor in the MDR-TB and XDR-TB ward at the Chest and TB Hospital revealed that in the large majority of drug-resistant cases, patients had a long treatment history and had developed resistance within their own bodies over time.[48] Though some patients do primarily become infected with pulmonary MDR-TB because of being exposed to drug-resistant bacilli, it is evident that significantly more patients become drug-resistant after defaulting or relapsing (DOTS, category II).

---

[47] Sharma, Surendra K., and Alladi Mohan. "Multidrug-Resistant Tuberculosis*: A Menace That Threatens To Destabilize Tuberculosis Control." *Chest Journal*. American College of Chest Physicians, July 2006. Web. 1 Nov. 2015. <http://journal.publications.chestnet.org/article.aspx?articleid=1084552&issueno=1&rss1>.

[48] Dr. Sahil Patel, Resident at Chest and TB Hospital. (2015, November 19th). Personal interview.

Treatment Adherence

Accessibility & availability

In 2003, a survey of tuberculosis patients showed that on average, people in Rajasthan traveled about 10.3 km for diagnosis and 4.6 km for treatment.[49] These are not necessarily far distances, however, they are averages that include urban, semi-urban, and rural environments. People who live in rural, remote areas certainly travel farther than 5 km, which may be difficult to do three times a week during office hours. Dr. Anil Gupta, a medical officer at the Chest and TB Hospital, mentioned that in rural areas it is very difficult for working men to go to their DOTS provider during the specified hours. Sometimes, when the patient goes to a sub-centre, PHC, or CHC, the doctor or DOTS provider simply isn't there.[50] Though this is not necessarily applicable to tuberculosis patients who reside in urban Rajasthan, some of the patients who were receiving treatment from the hospital in Jaipur were indeed from rural areas near the city. One patient who defaulted did report that he was not able to access medicine from the PHC in his village because he needed to show his medical records, but could not take time off from work to go to the hospital to retrieve them. However, neither availability nor accessibility was considered to be an outstanding factor regarding patients' treatment adherence, as solely one patient attributed these issues to their default status.

---

[49] Kumar, Dhirendra, L.P. Singh, Barun Kanjilal, and Jatinder Bir Singh. *TBC India*. Rep. Indian Institute of Health Management Research, Nov. 2003. Web. 29 Nov. 2015. <http://tbcindia.nic.in/pdfs/Accessibility%20and%20Utilisation%20of%20RNTCP%20Services%20by%20SCST%20Population%20-%20IIHMR.pdf>.

[50] Dr. Anil Gupta, Medical officer at Chest and TB Hospital. (2015, November 28th). Personal interview.

Social determinants & health-seeking behavior

Default patients

At the Chest and TB Hospital, many of the in-patient cases in the general ward were either freshly diagnosed or had been treated over the course of many years. It was found that many of those patients with long treatment histories had defaulted at least once, if not multiple times. As defined by the Revised National Tuberculosis Control Program, default patients have received anti-tuberculosis treatment for at least one month and have dropped out for at least two months. The previously discussed social determinants that contribute to a high prevalence of tuberculosis further complicate the disease via the patient's health-seeking behaviors following diagnosis.

Through patient interviews, it was determined that an exceedingly common factor among default patients was lack of education. One patient, an illiterate farmer, had been treated for his tuberculosis over the past few years. He actually defaulted three times during his treatment – once after 5 months, the second time after 3 months, and the most recent default was after 2 months of treatment. Each time, he could not go to his DOTS provider for solely one day because of urgent work. After this missed day of treatment, he had the misconception that he would need to completely restart the regimen, so he stopped taking the drugs completely. A few months later, he would go back to the doctor and start the same cycle over again.[51] In this case, the patient defaulted because he did not understand his treatment regimen and there was a misunderstanding. Doctors in India tell their tuberculosis patients that it is imperative to not miss any doses. However, it is not explained why this is so important or what can be done if one DOTS (treatment) day has to be missed.

[51] Interview with TB patients, Chest and TB Hospital.

Several other patients who shared the same demographic characteristics of being a farmer and uneducated were also default patients. One of them had been receiving treatment for the past 4 years. The most recent time, he reported taking ATT for 6 or 7 months (probably was on a 9 month regimen), but stopping because he was bleeding and thought the medicine wasn't working. Another patient who had been treated for his tuberculosis for the past 2.5 years first started treatment in his village, Namol. After a short period of treatment, the medicine wasn't working as quickly as he thought it would, so he decided that this doctor would not be able to treat him. He stopped all treatment for a few months and went to a different doctor. After receiving treatment from this doctor for 2 months, he stopped again for the same reason.[52] There were three more cases of default patients, very similar to these two. In these cases, the patients did not understand that the medicine takes a very long time to kill off all of the bacilli and relieve symptoms.

On the other hand, there was one very unique patient who did not seem to have a clear picture of his own treatment history. He was a stonecutter and his education status was unknown. When asked about his treatment history, he initially claimed that he took three full treatments, the first time for 6 months and the last two times for 8 months each. However, upon examination of his medical records, it was disclosed that he actually had defaulted three years ago after 1 month and two years ago after 3 months. Later, the patient reported that each of these times, he stopped taking the medication because he felt better and thought that his disease had been cured.[53] Many other default patients claimed that they also stopped treatment after feeling better. This is another large issue on the other end of the spectrum from what was previously stated. Dr.

[52] Interview with TB patients, Chest and TB Hospital.

[53] Interview with TB patients, Chest and TB Hospital.

Rajesh Meenan mentioned that many patients think that once their symptoms are relieved, patients think that they no longer need to take the chemotherapy drugs. It is very difficult to explain the concept of bacteria that still exist in the patient's lung cavities and could potentially be reactivated.[54]

Another issue that causes some patients to stop taking ATT is side effects. Though all possible side effects are explained at the beginning of treatment, sometimes patients independently decide to discontinue treatment. These side effects include nausea, vomiting, red-colored urine, jaundice, skin rashes, and more. When this happens, a small handful of patients decide to pursue treatment via homeopathic, rather than allopathic medicine. During patient interviews, four people revealed that they had defaulted after a few months of treatment because their bodies were "over-heating".[55] Some of the patients also said that during this time, it was very hot outside, which contributed their bodies' adverse reaction to the medication. This also ties into the Indian cultural concept of hot foods and cold foods, as it relates to a person's metabolism. In these cases, the patients stopped taking medicine because they felt like it was speeding up their metabolism too much.

Additionally, for some patients, it is impossible to continue taking ATT due to other medical conditions. As was previously mentioned, sometimes in co-infected HIV-TB patients, ART and ATT interfere with each other. Similarly, one patient, a housewife with no education, reported that after completing one full 6-month treatment regimen, she relapsed took treatment again for 4 months, but had to stop because she had another infection that needed to be

[54] Dr. Rajesh Meenan, Resident at Chest and TB Hospital.

[55] Interview with TB patients, Chest and TB Hospital.

prioritized.[56] Though this factor is not as immediately important, the possibility of pre-existing medical conditions does need to be considered.

Relapse patients

Relapse patients also belong to DOTS, category II. During, several interviews with relapse patients, it was found that many continued to smoke while taking the anti-tuberculosis drugs.[57] According to Dr. Sajan Singh, smoking may continue to damage the lungs and impair the patient's immunity, which essentially makes tuberculosis treatment an uphill battle. It is also possible, though not proven, that the tobacco itself interferes with the chemotherapy drugs.[58]

Though the researcher could not directly interview patients in the MDR-TB and XDR-TB wards, patients' medical histories were examined. Out of 16 patients with complete, recorded medical histories, 12 had a history of receiving non-DOTS treatment. In most cases, this means that the patient went to the private sector for treatment, although it could also indicate traditional or homeopathic medicine as well as self-medication. Either way, a history of non-DOTS treatment was found to be the largest commonality among patients who relapsed and have received treatment over the course of many years. The reason behind this lies in the nature of non-DOTS treatment. When a patient goes to a private healthcare provider, even though government notification of the case is mandatory, it is difficult to guarantee regimen completion. Without a DOTS provider to make sure that the patient is taking the medicine regularly, the danger of default becomes much more imminent. The type of treatment/medication that the patient receives is also not as highly regulated. In the wards, there were 13 patients who had

[56] Interview with TB patients, Chest and TB Hospital.

[57] Interview with TB patients, Chest and TB Hospital.

[58] Dr. Sajan Singh, Chest and TB Hospital.

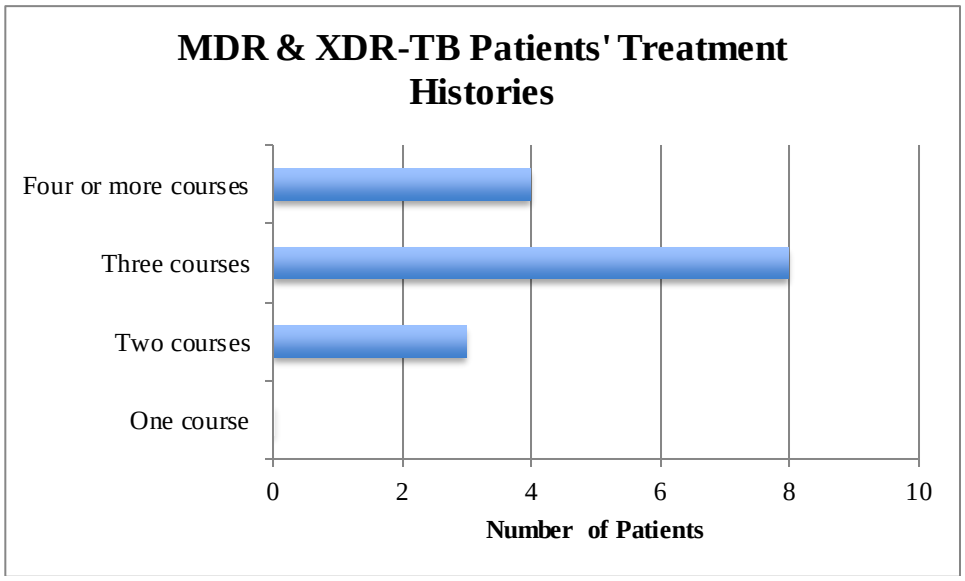
gone through at least one course of non-DOTS treatment and already had developed drug resistance to isoniazid and rifampicin by the time they came to the Chest and TB Hospital for the first time (MDR-TB).[59]

One other important common characteristic among drug-resistant patients was the duration and level of complexity of their treatment. For example, an XDR-TB patient who had been receiving treatment for 10 years had the following treatment history: 10 years back, took non-DOTS treatment for 5.5 months with no improvement; then took non-DOTS treatment for 1 year with partial improvement; 5 years ago, took DOTS treatment for category I for 6 months, but still sputum-positive; 4 years ago, took DOTS for 9 months, then non-DOTS again; 3 years ago became category IV, MDR-TB and completed 2 year DOTS course; is now XDR-TB and is on treatment. After 10 years of treatment and a mix of seven DOTS and non-DOTS courses, this patient became extensively drug-resistant. Though not many other drug-resistant patients had treatment histories to this extent, they certainly were still complicated.[60] As Figure 6 demonstrates, out of 15 patients with complete histories, 8 had received three courses of treatment and none were receiving treatment for the first time. Each case was found to be unique, but the common denomination was a lengthy, messy history of defaulting, relapsing, and mixed DOTS and non-DOTS treatment. It is extremely likely that drug-resistance was internally developed within each of these patients due to the nature of their treatment histories.

[59] *In-patient Records, TB Wards*.

[60] *In-patient Records, TB Wards*.

Figure 6: Number of courses taken by MDR & XDR-TB patients, Chest and TB Hospital[61]



Stigma and understanding TB

Another important factor to consider regarding treatment adherence is how stigma and discrimination may influence health-seeking behaviors. Mrs. Priya Mody, the TB counselor at the Chest and TB Hospital claimed that some of her patients and their loved ones did express fear if they did not understand the disease or how it spreads.[62] In his personal experience both in Jaipur and a district hospital in a rural part of Rajasthan, Dr. Sajan Singh observed that some patients did not pursue treatment at their DOTS provider and defaulted because of stigma.[63] This was because they feared what would happen if the entire community knew that they had tuberculosis. At times, others, including family members and friends, keep their distance and

[61] *In-patient Records, TB Wards*.

[62] Mrs. Priya Mody, TB Counselor at Chest and TB Hospital. (2015, November 21st). Personal interview with translator assistance.

[63] Dr. Sajan Singh, Chest and TB Hospital.

isolate patients because they fear getting the disease and oftentimes do not exactly understand how it is transmitted from one person to another.

Upon interviewing patients at the Chest and TB Hospital, it became apparent that either social stigma was not an important factor regarding health-seeking behavior or that, quite understandably, it was something that patients were not comfortable speaking about in the given setting. Because of cross-cultural differences and quick translation between Hindi and English, there also may have been miscommunication about what exactly was being asked. Regardless, a small handful of patients did report facing social changes; out of 27 interviewed patients, 5 reported facing any kind of social change. Four of these patients reported facing stigma from non-immediate family members and only one reported facing discrimination from immediate family. One other patient actually claimed that he now does not face any stigma because his friends think that he no longer has TB, since he has gone through three courses of treatment. Even though almost one fifth of these patients did face social changes to an extent, it may not have directly influenced their treatment adherence. Upon being asked why they defaulted treatment, no patients reported that it was because of any social changes in their life.[64] Hence, social stigma was not found to be a decisive factor in determining health-seeking behavior, at least in the context of urban Rajasthan.

RNTCP & DOTS Policies

In order to gain more insight into how current government schemes address the previously discussed issues, the researcher interviewed Dr. Nirav Banerjee, a representative of

[64] Interview with TB patients, Chest and TB Hospital.

the World Health Organization at the State TB Cell, Directorate of Health and Family Welfare in Rajasthan. According to Dr. Banerjee, as a response to the high endemic levels of tuberculosis, emergence of drug resistance, and issues with the older program, the government piloted the Revised National Tuberculosis Control Project, or RNTCP, in 1997. This program was conceptualized in 1993 after a countrywide TB emergency was declared in 1992. The government of India, alongside other agencies like the World Health Organization, reviewed the earlier program from 1962, the National TB Control Program, and addressed its shortcomings.[65]

Primarily, the older scheme had suboptimal supervision in terms of monitoring. The way in which the drugs were dispensed was also unsuccessful. At dispensaries, patients were given medication for a fortnight, a week, or sometimes a month, and therefore were completely responsible for taking it on their own time. In addition to this, the regimen was daily and rifampicin was not used, so the quality of the drugs was also suboptimal. There was no systemic monitoring of the events regarding treatment; there was a district TB officer, but no supportive staff earmarked below him at the sub-district level and below.[66]

As a response to these issues, the design of RNTCP had many changes, relying on five main components. Primarily, there was much more administrative support, meaning that besides the district officer, there was support down to the level of PHCs and CHCs. Another key component was good quality sputum microscopy diagnosis, meaning that the facilities for diagnosis were expanded and improved. These facilities became available at PHCs and a large amount of staff was trained to perform the techniques. The third component was an uninterrupted supply of good quality drugs tested in labs; this was revolutionary because it reduced issues that

[65] Dr. Nirav Banerjee, WHO representative at State TB Cell, Directorate of Health and Family Welfare, Rajasthan. (2015, December 2nd). Personal interview.

[66] Dr. Nirav Banerjee, WHO representative at State TB Cell, Directorate of Health and Family Welfare, Rajasthan.

patients may have faced regarding availability of treatment. The next part was DOTS, or directly observed therapy, short-course. In contrast to the completely unsupervised previous method, this ensured that patients took their medication by requiring that each registered patient takes his or her treatment three times a week in front of a DOTS provider. The last component was supervision and monitoring in a systematic way, as well as the implementation of sub-district TB control units.[67] A key theme throughout these revised components, the decentralization of facilities and resources has proven to be very important.

After the pilot project was launched successfully in 1997 in state capitals (including Jaipur), countrywide expansion of RNTCP began in 1998. By 2000, the entire state of Rajasthan was covered, the fastest expansion of TB control coverage ever done. Phase one of the program lasted until September 2005; RNTCP is now currently in its third phase. RNTCP has had greatly effective and has consistently been able to maintain a nationwide treatment success rate of 85%, though much more still needs to be done.[68]

MDR-TB

Improved facilities for drug-resistance testing have been pivotal for addressing the growing issue of drug resistance recently in India. According to Dr. Banerjee, in 2008, the government introduced a new scheme for the official management of drug-resistant tuberculosis. Gujarat and Maharashtra were the first two states to adopt the plan and Rajasthan introduced it in March of 2009. A lab for testing for drug resistance through patients' solid sputum cultures was accredited in Jaipur. However, testing for drug resistance through solid cultures has proven to be a lengthy, inefficient method. In 2010, LPA (line probe assay) labs were established at SMS

[67] Dr. Nirav Banerjee, WHO representative at State TB Cell, Directorate of Health and Family Welfare, Rajasthan.

[68] Dr. Nirav Banerjee, WHO representative at State TB Cell, Directorate of Health and Family Welfare, Rajasthan.

Medical College in Jaipur, as well as in Ajmer and Jodhpur; LPA tests for drug resistance are much more efficient. Another development that has been key in the battle against drug resistance is the introduction of second-line DST (drug-susceptibility testing) at SMS Medical College last year, which is greatly helpful with diagnosing XDR-TB. Rajasthan is likely to get more machines next year for detecting rifampicin resistance.[69]

Regarding treatment adherence, Dr. Banerjee insisted that since there is currently very centralized access to counseling, which is very important in determining the health-seeking behaviors of patients. The decentralization of treatment services and counseling will help many patients adhere to treatment, rather than to default and risk developing drug resistance over time. As mentioned earlier, many patients who relapsed or defaulted had pursued non-DOTS treatment. Moving forward, treatment completion can only be ensured if patients pursue government services, rather then services in the private sector. The likelihood of this happening heavily depends on how patient-friendly the treatment is, meaning the government needs to actively encourage tuberculosis patients to pursue DOTS services. In addition to the private sector, some patients attempt to medicate themselves. To address this, Schedule H1 was been enforced in India and the government of Rajasthan has endorsed and implemented this – there is a list of 46 medicines that Indian citizens technically need a prescription for in order to purchase at the chemist. This includes all first and second-line TB drugs. However, because of the lack of monitoring on the ground, the implementation of this legislation has not been successful. Patients are actually still being sold chemotherapy drugs without the prescription of a doctor.[70] Over time, stricter regulation will be necessary.

---

[69] Dr. Nirav Banerjee, WHO representative at State TB Cell, Directorate of Health and Family Welfare, Rajasthan.

[70] Dr. Nirav Banerjee, WHO representative at State TB Cell, Directorate of Health and Family Welfare, Rajasthan.

"At-risk" groups

Dr. Banerjee and the researcher also discussed current policies addressing the aforementioned "at-risk" groups for tuberculosis. NACP, the National AIDS Control Programme, has recently paired with RNTCP in order to formulate policies for HIV-TB co-infected patients. The aim is to find ways to reduce the high endemic levels of HIV-TB co-infected patients, however there are very few policies that actually address this from a preventative level. The large focus is on tracking current patients – much still needs to be done from a primary healthcare as well as a social standpoint.

In 2014, the policy of RNTCP was revised and the government issued mandatory testing of all TB patients for HIV. HIV patients are also regularly tested for TB using the aforementioned improved testing facilities. One other practice under the newly revised policy is in regards to how doctors triage a co-infected patient's treatment regimen. Now, ART, anti-retroviral therapy, is given to co-infected patients irrespective of their CD4 counts; this was previously a limiting factor. In practice, ATT is typically started first and when the patient shows tolerance, ART is added (usually 2 weeks later).[71] The collaboration between NACP and RNTCP has been successful, however there needs to be more of a focus on policy regarding seasonal and transitory migrants. The government must track these patients more effectively, improve living conditions in urban slums, and better connect migrants with healthcare facilities.

RNTCP also addresses smokers as an "at-risk" group for tuberculosis. The National Tobacco Control Programme was launched about 3 years ago and there are now linkages between the program and RNTCP. In 2010, the government formulated a policy of universal access, meant to ensure treatment services to a subset of "at-risk" patients, including smokers.

[71] Dr. Nirav Banerjee, WHO representative at State TB Cell, Directorate of Health and Family Welfare, Rajasthan.

However, at the implementation stage, there is still a huge gap. Campaigns concerning awareness of how smoking affects pulmonary health and the risk of tuberculosis will continue to be spread throughout the country in future years. Currently, there is the COTPA Act, the Cigarettes and Other Tobacco Products Act, which was implemented in 2003. This act prohibits the smoking of tobacco in public places, except in smoking zones and open spaces. The advertisement of tobacco products is prohibited. Tobacco products may not be sold to anyone under the age of 18 years and tobacco may not be sold within 100 meters from a school or university.[72] However, the technical aspects of this act have not been carried out well and the full implementation will take some time. There is a high level of awareness among government officials and policymakers, however, this does not exist among the general public. The COTPA Act has had little impact in the last 12 years and much needs to change. Aside from tightening up current policies, there needs to be a more aggressive campaign that limits the use of tobacco. Namely, the police force needs to fine more people who are breaking the law in any way, especially tobacco vendors.

Though less of a preventative measure, the efforts regarding silicotuberculosis patients have been a little more effective. Because of successful decentralization, there currently is a silicosis board at each district level. The board consists of four doctors: a chest and TB expert, a radiologist, a medical jurist, and an internist. Only available in the state of Rajasthan, the board analyzes the patient's diagnosis and determines whether they will be able to be compensated. If the patient has been diagnosed with government facilities and is determined to be silocotic, they are compensated with 1 to 1.5 lakhs, or 100,000 to 150,000 Indian rupees.[73] However, like many other government schemes, there are no preventative measures taken to ensure that miners, stonecutters, and other laborers are not exposed to the environmental injustice that put them at

[72] Dr. Nirav Banerjee, WHO representative at State TB Cell, Directorate of Health and Family Welfare, Rajasthan.

[73] Dr. Nirav Banerjee, WHO representative at State TB Cell, Directorate of Health and Family Welfare, Rajasthan.

risk in the first place. In the future, it will be key to implement policies that tackle this larger issue. Namely, there needs to be legislation that incentivizes mining and labor companies to provide safer environmental conditions for their workers, i.e. more limited working hours, more protective equipment.

Conclusion

The goal of this research was to explore the social determinants of health that may be linked to the likelihood of developing tuberculosis, as well as the health-seeking behaviors that could influence treatment adherence. Through the analysis of medical records at the Chest and TB Hospital, the researcher was able to clearly identify which social determinants of health were correlated with a higher risk of tuberculosis, as well as areas in which there was little to no correlation. "At-risk" populations in Rajasthan were also identified and discussed. Through patient interviews at the hospital, reasons for default were analyzed, alongside the patients' notable medical history. Through this, the most common reasons for patients defaulting and relapsing were determined. Lastly, current legislation and policies, including RNTCP and DOTS were examined and future suggestions were provided.

Research challenges & limitations

Throughout the research period, there were several limitations. One of the biggest barriers was translation. Since the Chest and TB Hospital is a government facility catering to hundreds of patients every day, the English-speaking doctors on staff had limited availability. The researcher was not able to find a translator with prior knowledge of public health, so it was

difficult to explain the project as well as the interview questionnaire. In addition to this, it is possible that some of the questions may have been lost in translation during patient interviews. When the researcher tried to inquire about any social stigma or discrimination that patients have faced, the patient's attendants were either part of the interview or were nearby. It is quite possible that being in front of so many people and having a foreign researcher asking, the patient did not feel comfortable discussing this personal issue.

One other limitation during this study was due to policies regarding patient confidentiality. The researcher was unable to receive any data regarding HIV-TB co-infected patients because this information is highly protected. The last limitation was that the researcher was unable to interview MDR-TB and XDR-TB patients. Though it would certainly pose a risk to the researcher's health as well as others', it would have been very helpful to be able to hear about reasons for why they may have defaulted. It also would have been interesting to speak to these patients about their understanding of what drug resistance means, in order to gain a better understanding of how they view their own disease.

Recommendations for further study

In terms of future study, the researcher hopes to invest more time analyzing the records of MDR-TB and XDR-TB patients. As it was previously observed that the large majority of these patients have along history of non-DOTS treatment, it would be helpful to follow up with these patients in a survey and to ask specifically what this treatment consisted of. Namely, whether the patient pursued homeopathy, self-medication, treatment in the private sector, etc. An interview with a TB doctor in the private sector would be helpful in terms of gaining more insight into what non-DOTS private treatment may specifically consist of and how treatment is monitored.

In addition to this, the researcher would also hope to spend time speaking to government officials about current policies that may affect tuberculosis prevalence. Since the researcher primarily spoke to a WHO representative at the State TB Cell about this issue, it would be greatly helpful to also discuss the matter with a representative from the National AIDS Control Programme, the National Tobacco Control Programme, and the silicosis board for the district of Jaipur.

Acknowledgements

Primarily, I would like to thank the entire staff of the Chest and TB Hospital in Jaipur, including superintendent Dr. Jainav, as well as all of the kind nurses, doctors, and administrators who were so wonderfully helpful. Aside from the resources and valuable information that I received from individuals at this institution, I truly appreciate immense support and hospitality that was shown towards me. Without fail, every time I went to the hospital, someone invited me into their office to have chai and chat, making me much more comfortable in what was initially an unfamiliar environment. Without the kindness of these people and the patience and cooperation from patients during interviews, I would not have been able to complete any of this research. I would like to acknowledge Dr. Sharma for being such an incredible project advisor and for being so hospitable. As a hopeful future physician, I enjoyed learning from someone who is so accomplished and knowledgeable about respiratory medicine.

I would also like to thank Dr. Choudhary from the Directorate of Health and Family Welfare for providing contacts at various institutions in Jaipur and for helping me with the organization of my project schedule. I would like to acknowledge my professors at the School for International Training in Delhi for being so immensely supportive and for preparing me for

this research period. Thank you to Abid Ji, for providing me with contacts in Jaipur, for problem-solving and providing moral support every time an issue emerged. To Azim Ji for sharing public health and human rights wisdom and being a phenomenal academic director. To Archana Ji for giving the best hugs and being so supportive and cheerful. To Bhavna Ji for giving incredible life advice and sharing such a great sense of humor. To Goutam Ji for sharing so many interesting stories and for telling the best jokes around. Thank you to all for providing such a strong network of support and for making this semester so special.

APPENDIX A

Chest and TB Hospital – Patient Records from Wards[74]

Admitted patients, general TB male ward

Patient #1
Age: 53 years old
Sex: male
Occupation: milk vendor
Diagnosis: treated PTB, hemoptysis, left destroyed lung

Patient #2
Age: 72 years old
Sex: male
Occupation: wood cutter
Marital status: married
Children: none
Lifestyle behavior: ex-smoker; has stopped since one year
Diagnosis: treated PTB with COPD

Patient #3
Age: 25 years old
Sex: male
Occupation: farmer
Marital status: married
Children: none
Lifestyle behavior: occasional smoker, alcoholic
Diagnosis: PTB, category II (relapse)

Patient #4
Age: 60 years old
Sex: male
Occupation: helper/messenger at corporate plant
Marital status: married
Children: 4 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: left-sided pleural effusion (under process of diagnosis)

Patient #5
Age: 36 years old
Sex: male
Occupation: stone worker for 2 years
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: acute silicosis

Patient #6
Age: 73 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 10 children
Lifestyle behavior: ex-smoker, alcoholic
Diagnosis: treated PTB with COPD and hemoptysis

Patient #7
Age: 30 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 2 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: treated PTB with COPD

Patient #8
Age: 50 years old
Sex: male
Occupation: tailor
Marital status: married
Children: 3 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: treated PTB with COPD

Patient #9
Age: 60 years old
Sex: male
Occupation: food vendor
Marital status:
Children:
Lifestyle behavior: smoker, non alcoholic
Diagnosis: silico-PTB, category I with COPD

[74] Though extra-pulmonary tuberculosis cases are included in data, only pulmonary cases were considered upon analysis.

Patient #10
Age: 55 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 4 children
Lifestyle behavior: ex-smoker, alcoholic
Diagnosis: left-sided pleural effusion, EPTB

Patient #11:
Age: 32 years old
Sex: male
Occupation: student
Marital status: married
Children: 2 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: PTB, category II, type I diabetes, hemoptysis

Patient #12:
Age: 45 years old
Sex: male
Occupation: wood cutter
Marital status: married
Children: 6 children
Lifestyle behavior: smoker, non alcoholic
Diagnosis: PTB, relapse case with COPD

Patient #13:
Age: 20 years old
Sex: male
Occupation: manual laborer
Marital status: married
Children: 1 child
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: PTB default case, left-sided pyopneumothorax

Patient #14:
Age: 74 years old
Sex: male
Occupation: attendant at gas station
Marital status: married
Children: 4 children
Lifestyle behavior: chronic smoker, non-alcoholic
Diagnosis: PTB, bilateral pleural effusion

Patient #15:
Age: 50 years old
Sex: male
Occupation: bus driver
Marital status: married
Children: 3 children
Lifestyle behavior: ex-smoker, ex alcoholic
Diagnosis: PTB

Patient #16:
Age: 65 years old
Sex: male
Occupation: manual laborer
Marital status: married
Children: 5 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: treated PTB with hemoptysis

Patient #17:
Age: 45 years old
Sex: male
Occupation: stonecutter for 20 years
Marital status: married
Children: 2 children
Lifestyle behavior: ex-smoker, ex alcoholic
Diagnosis: PTB relapse with silicosis and COPD

Patient #18:
Age: 50 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 6 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: treated PTB with recurrent pyopneumothorax

Patient #19:
Age: 45 years old
Sex: male
Occupation: farmer

Marital status: married
Children: 2 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: PTB defaulter

Patient #20:
Age: 38 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 4 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: treated PTB with COPD

Patient #21:
Age: 64 years old
Sex: male
Occupation: stone work for 35 years
Marital status: married
Children: none
Lifestyle behavior: occasional smoker, non-alcoholic
Diagnosis: treated PTB with silicosis

Patient #22:
Age: 30 years old
Sex: male
Occupation: manual laborer
Marital status: married
Children: 2 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: left-sided pleural effusion with systemic hypertension and anemia

Patient #23:
Age: 50 years old
Sex: male
Occupation: general store grocer
Marital status: married
Children: 5 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: PTB relapse with COPD

Patient #24:
Age: 72 years old
Sex: male
Occupation: driver
Marital status: married
Children: 2 children
Lifestyle behavior: chronic smoker, non-alcoholic
Diagnosis: PTB with COPD, type II respiratory failure

Patient #25:
Age: 72 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 3 children
Lifestyle behavior: chronic smoker, non-alcoholic
Diagnosis: PTB with right-sided pleural effusion

Patient #26:
Age: 40 years old
Sex: male
Occupation: police constable
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: left-sided pleural effusion, EPTB

Patient #27:
Age: 65 years old
Sex: male
Occupation: Jeep driver
Marital status: married
Children: 6 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: PTB with COPD, ATT intolerance (vomiting, jaundice)

Patient #28:
Age: 72 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 2 children
Lifestyle behavior: smoker, non alcoholic
Diagnosis: PTB with COPD

Patient #29:
Age: 60 years old
Sex: male
Occupation: stone worker for 20 years
Marital status: married
Children: 6 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: follow-up case PTB, category II with silicosis, type II respiratory failure

Patient #30:
Age: 45 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 4 children
Lifestyle behavior: ex-smoker, ex alcoholic
Diagnosis: treated PTB with left upper lobe aspergilloma with hemoptysis

Patient #31:
Age: 40 years old
Sex: male
Occupation: tea shop
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, ex-alcoholic, chronic tobacco chewer
Diagnosis: PTB, type I respiratory failure

Patient #32:
Age: 18
Sex: male
Occupation: student
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: PTB defaulter, right-sided pyopneumothorax

Patient #33:
Age: 55 years old
Sex: male
Occupation: pawn shop
Marital status: married
Children: 2 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: right-sided pleural effusion, PTB

Patient #34:
Age: 48 years old
Sex: male
Occupation: retired police officer
Marital status: married
Children: 5 children
Lifestyle behavior: non-smoker, alcoholic
Diagnosis: PTB defaulter with COPD

Patient #35:
Age: 60 years old
Sex: male
Occupation: stone worker for 5 years
Marital status: married
Children: 4 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: follow-up case of PTB, category II with hemoptysis

Patient #36:
Age: 45 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 2 children
Lifestyle behavior: ex-smoker, ex alcoholic
Diagnosis: treated PTB with hemoptysis

Patient #37:
Age: 48 years old
Sex: male
Occupation: manual laborer
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, chronic alcoholic
Diagnosis: PTB

Patient #38:
Age: 28 years old
Sex: male
Occupation: manual laborer
Marital status: married

Children: 1 child
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: suspected abdominal EPTB, severe anemia

Admitted patients, general TB female ward

Patient 39:
Age: 40 years old
Sex: female
Occupation: diamond polisher
Marital status: married
Children: 2 children
Lifestyle behavior: chronic smoker, non-alcoholic
Diagnosis: treated PTB with obstructive airway disease

Patient 40:
Age: 22 years old
Sex: female
Occupation: housewife
Marital status: married
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: follow-up PTB case with category II DOTS

Patient 41:
Age: 32 years old
Sex: female
Occupation: housewife
Marital status: married
Children: 2 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: follow-up case PTB, obstructive airway disease

Patient 42:
Age: 28 years old
Sex: female
Occupation: housewife
Marital status: married
Children: 1 child
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: follow-up case PTB, developed psychosis

Patient 43:
Age: 72 years old
Sex: female
Occupation: homemaker
Marital status: widowed
Children: 10 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: follow-up case PTB

Patient 44:
Age: 40 years old
Sex: female
Occupation: housewife
Marital status: married
Children: 3 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: defaulter PTB, category II

Patient 45:
Age: 20 years old
Sex: female
Occupation: student
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: follow-up case from private sector, PTB, pyopneumothorax

Patient 46:
Age: 30 years old
Sex: female
Occupation: housewife
Marital status: married
Children: 1 child
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: follow-up case from private sector, being tested now, PTB

Admitted & recently discharged patients, MDR-TB & XDR-TB male ward

Patient 47:
Age: 21 years old
Sex: male
Occupation: student
Marital status: unmarried
Children: none

Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: treated for 6 months, then MDR-TB

Patient 48:
Age: 50 years old
Sex: male
Occupation: stone cutter for 20 years
Marital status: married
Children: 3 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: treatment for 2 years, MDR-TB with silicosis and diabetes

Patient 49:
Age: 23 years old
Sex: male
Occupation: construction worker
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: treatment for 2 years, XDR-TB patient

Patient 50:
Age: 25 years old
Sex: male
Occupation: painter
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: treatment for past 10 years, XDR-TB

Patient 51:
Age: 20 years old
Sex: male
Occupation: laborer
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, alcoholic
Diagnosis: MDR-TB
Contact: grandfather had TB

Patient 52:
Age: 30 years old
Sex: male
Occupation: farmer
Marital status: married
Children: unknown
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: follow-up XDR-TB patient, treated for 8 years

Patient 53:
Age: 48 years old
Sex: male
Occupation: laborer, stone cutting
Marital status: married
Children: 4 children
Lifestyle behavior: has quit smoking for 6 months, alcoholic
Diagnosis: follow-up case MDR-TB

Patient 54:
Age: 45 years old
Sex: male
Occupation: landlord
Marital status: married
Children: 9 children
Lifestyle behavior: has quit smoking for 3 years, non-alcoholic
Diagnosis: MDR-TB

Patient 55:
Age: 50 years old
Sex: male
Occupation: stone cutter for 30 years
Marital status: married
Children: 8 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: MDR-TB

Patient 56:
Age: 25 years old
Sex: male
Occupation: shop-keeper
Marital status: married
Children: 1 child
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: follow-up MDR-TB

Patient 57:
Age: 27 years old
Sex: male
Occupation: unknown
Marital status: unmarried
Children: none
Lifestyle behavior: smoker, alcoholic
Diagnosis: MDR-TB, HIV positive

Patient 58:
Age: 74 years old
Sex: male
Occupation: unemployed
Marital status: married
Children: 3 children
Lifestyle behavior: smoker, non alcoholic
Diagnosis: MDR-TB

Patient 59:
Age: 45 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 3
Lifestyle behavior: smoker, non alcoholic
Diagnosis: MDR-TB

Patient 60:
Age: 60 years old
Sex: male
Occupation: store selling garments
Marital status: married
Children: 3 children
Lifestyle behavior: ex-smoker, occasional alcoholic
Diagnosis: MDR-TB

Patient 61:
Age: 36 years old
Sex: male
Occupation: construction worker
Marital status: married
Children: 2 children
Lifestyle behavior: ex-smoker, ex alcoholic
Diagnosis: MDR-TB

Patient 62:
Age: 40 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 2 children
Lifestyle behavior: non-smoker, occasional alcoholic
Diagnosis: MDR-TB

Patient 63:
Age: 35 years old
Sex: male
Occupation: stone cutter for 15 years
Marital status: married
Children: 6 children
Lifestyle behavior: smoker, non alcoholic
Diagnosis: MDR-TB with silicosis

Patient 64:
Age: 50 years old
Sex: male
Occupation: stone cutter
Marital status: married
Children: 2 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: silicosis with MDR-TB
Contact: brother had TB

Patient 65:
Age: 50 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 4 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: MDR-TB

Patient 66:
Age: 65 years old
Sex: male
Occupation: farmer
Marital status: married
Children: 3 children
Lifestyle behavior: smoker, non-alcoholic
Diagnosis: follow-up case of MDR-TB

Patient 67:
Age: 24 years old

Sex: male
Occupation: farmer
Marital status: unmarried
Children: none
Lifestyle behavior: smoker, occasional alcoholic
Diagnosis: MDR-TB

Patient 68:
Age: 45 years old
Sex: male
Occupation: driver
Marital status: married
Children: 3 children
Lifestyle behavior: smoker, alcoholic
Diagnosis: MDR-TB

Patient 69:
Age: 25 years old
Sex: male
Occupation: unknown
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: XDR-TB, treatment for 3 years

Patient 70:
Age: 23 years old
Sex: male
Occupation: construction worker
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: MDR-TB

Patient 71:
Age: 68 years old
Sex: male
Occupation: tailor
Marital status: married
Children: 4 children
Lifestyle behavior: smoker, alcoholic
Diagnosis: MDR-TB

Patient 72:
Age: 60 years old
Sex: male
Occupation: construction worker
Marital status: married
Children: 4 children
Lifestyle behavior: ex-smoker, non-alcoholic
Diagnosis: MDR-TB
Contact: wife had TB

Patient 73:
Age: 45 years old
Sex: male
Occupation: stone worker for 4 years
Marital status: married
Children: 2 children
Lifestyle behavior: smoker, alcoholic
Diagnosis: MDR-TB with silicosis

Patient 74:
Age: 18 years old
Sex: male
Occupation: student
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: MDR-TB

Patient 75:
Age: 28 years old
Sex: male
Occupation: student
Marital status: married
Children: 1 child
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: XDR-TB

Admitted patients, MDR-TB & XDR-TB female ward

Patient 76:
Age: 23 years old
Sex: female
Occupation: student
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: was MDR-TB, became XDR-TB

Patient 77:

Age: 45 years old
Sex: female
Occupation: housewife
Marital status: married
Children: 4 children
Lifestyle behavior: smoker for 10 years, non-alcoholic
Diagnosis: MDR-TB

Patient 78:

Age: 28 years old
Sex: female
Occupation: housewife
Marital status: married
Children: 3 children
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: follow-up MDR-TB, needs continuous oxygen

Patient 79:

Age: 16 years old
Sex: female
Occupation: student
Marital status: unmarried
Children: none
Lifestyle behavior: non-smoker, non-alcoholic
Diagnosis: MDR-TB

APPENDIX B

Chest and TB Hospital – Patient Records from TB Counselor Registrar

Male records

Patient 80:
Age: 50 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 81:
Age: 61 years old
Gender: male
Education: primary school
Marital status: married
Occupation: laborer/farmer

Patient 82:
Age: 60 years old
Gender: male
Education: secondary school
Marital status: married
Occupation: unemployed

Patient 83:
Age: 12 years old
Gender: male
Education: primary school
Marital status: unmarried
Occupation: student

Patient 84:
Age: 60 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 85:
Age: 35
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 86:
Age: 25 years old
Gender: male
Education: primary school
Marital status: married
Occupation: laborer/farmer

Patient 87:
Age: 27 years old
Gender: male
Education: secondary school
Marital status: married
Occupation: skilled worker

Patient 88:
Age: 65 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: unemployed

Patient 89:
Age: 60 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 90:
Age: 31 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 91:
Age: 11 years old
Gender: male
Education: primary school
Marital status: unmarried
Occupation: student

Patient 92:
Age: 55 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 93:
Age: 60 years old
Gender: male
Education: illiterate

Marital status: married
Occupation: laborer/farmer

Patient 94:
Age: 40 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 95:
Age: 30 years old
Gender: male
Education: secondary school
Marital status: unmarried
Occupation: laborer/farmer

Patient 96:
Age: 20 years old
Gender: male
Education: secondary school
Marital status: unmarried
Occupation: laborer/farmer

Patient 97:
Age: 33 years old
Gender: male
Education: primary school
Marital status: married
Occupation: laborer/farmer

Patient 98:
Age: 53 years old
Gender: male
Education: primary school
Marital status: married
Occupation: laborer/farmer

Patient 99:
Age: 55 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 100:
Age: 70 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: unemployed

Patient 101:
Age: 45 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 102:
Age: 91 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: unemployed

Patient 103:
Age: 40 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 104:
Age: 35 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 105:
Age: 40 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 106:
Age: 48 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 107:
Age: 30 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 108:
Age: 42 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 109:
Age: 45 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 110:
Age: 23 years old
Gender: male
Education: secondary school
Marital status: married
Occupation: unknown

Patient 111:
Age: 55 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 112:
Age: 26 years old
Gender: male
Education: secondary school
Marital status: married
Occupation: laborer/farmer

Patient 113:
Age: 30 years old
Gender: male
Education: primary school
Marital status: married
Occupation: laborer/farmer

Patient 114:
Age: 70 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: unemployed

Patient 115:
Age: 70 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 116:
Age: 73 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: unemployed

Patient 117:
Age: 55 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Patient 118:
Age: 65 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: unemployed

Patient 119:
Age: 55 years old
Gender: male
Education: illiterate
Marital status: married
Occupation: laborer/farmer

Female records

Patient 120:
Age: 23 years old
Gender: female
Education: primary school
Marital status: married
Occupation: housewife

Patient 121:
Age: 29 years old
Gender: female
Education: secondary school
Marital status: married
Occupation: housewife

Patient 122:
Age: 65 years old
Gender: female
Education: illiterate
Marital status: widowed
Occupation: housewife

Patient 123:
Age: 20 years old
Gender: female
Education: illiterate
Marital status: married
Occupation: housewife

Patient 124:
Age: 30 years old
Gender: female
Education: illiterate
Marital status: married
Occupation: housewife

Patient 125:
Age: 60 years old
Gender: female
Education: illiterate
Marital status: married
Occupation: housewife

Patient 126:
Age: 45 years old
Gender: female
Education: illiterate
Marital status: married
Occupation: housewife

Patient 127:
Age: 33 years old
Gender: female
Education: illiterate
Marital status: married
Occupation: housewife

Patient 128:
Age: 15 years old
Gender: female
Education: secondary school
Marital status: unmarried
Occupation: student

Patient 129:
Age: 25 years old
Gender: female
Education: illiterate
Marital status: married
Occupation: housewife

Patient 130:
Age: 35 years old
Gender: female
Education: primary school
Marital status: married
Occupation: housewife

APPENDIX C

Chest and TB Hospital – Patient Interviews from Wards

Patient 131:

- 18 years old, male, student, Muslim, has studied to 11th standard (higher secondary), from Jaipur, non-smoker, non-alcoholic
- PTB, has only been diagnosed for one week and has just started treatment; is feeling hopeful
- No change in social life
- Getting free medicine from government, everything is free including testing and bed
- Doctor hasn't told him how long treatment will last

Patient 132:

- 47 years old, male, farmer, from nearby district in Rajasthan, quit smoking and alcohol 6 months back
- TB for last few years, treatment in nearby Altar district; he continued treatment 3 different times
- Couldn't complete the treatment all 3 times; first time only took for 5 months, second time for 3 months, third time for 2 months
- He had urgent work and wasn't able to go to the DOTS provider; he thought that if you miss treatment for one day, you have to start all over, so he stopped all treatment each time he had to miss only one day
- He eats separately from his family but doesn't necessarily feel social exclusion
- No interruption in his work
- Doctor explained everything to him

Patient 133:

- 55 years old, was farmer but unemployed, Hindu, from Tonk, no study, 1 year back was a smoker and an alcoholic
- Admitted four days ago, but had TB treatment for 4 years. 1.5 years back, he started treatment, took for 6-7 months, blood came out when he took medicine and he thought that it was not working, so he stopped taking; he relapsed and had to come here to the hospital
- He had to stop farming after he got TB
- He has separated utensils for eating, but he eats with his family; they have a special jar for the sputum

Patient 134:

- 65 years old, male, farmer, primary school education, Hindu, from Haryana state, 1.5 years back was smoker and alcoholic
- TB patient for the last 2.5 years; first treatment in village Namol; after a while of treatment, he was not getting better and he thought that this doctor would not be able to treat him, so he stopped treatment and went to another doctor; he saw another doctor and stopped after 2 months because he thought that this doctor would not be able to cure him either since the medication wasn't working quickly; he has been on treatment for the last year and has started to feel better
- He has separated utensils from the rest of his family, but does not face any social exclusion
- He could not work after he got TB and the doctor told him that one of his lungs is completely damaged and he has 3-4 years to live

Patient 135:

- 30 years old, male, Hindu, from 70 km away, stone-cutter, smoker but has quit for 1 year
- Silicosis and PTB, has started treatment 6-7 years back in a private hospital; took treatment for full 6 months, but kept stone-crushing, smoking, and drinking alcohol; he was well for about 2-3

months, then took treatment for a full 8 months and then 8 months again, then took treatment for 8 months, however, medical records say that he defaulted 3 years back after 1 month, 2 years back after 3 months; when asked why, he said that he felt better and he stopped taking the medicine because he thought that he had been cured
- He has been able to work this entire time and has not faced any problems socially
- This course that he is currently on will take up to 2 years

Patient 136:
- 65 years old, male, farmer, Hindu, uneducated, 15 years back left smoking and drinking
- 15 years back, he got 2 courses of 6 month treatment but he did not leave smoking or alcohol; he is a default patient (category II); he stopped taking medicine after 4-5 months because his body was "over-heating" so he stopped taking it even though he was supposed to for 9 months
- He has reported that there are no social changes because his friends think that since he has been treated so many times, he no longer has TB
- He has not been able to work for the past 10 years

Patient 137:
- 50 year old male, from Karolin nearby district (180 km away), Hindu, uneducated, farmer
- PTB defaulter, extremely malnourished; has had TB for last 2.5 years and after 4-5 months, he was feeling good, so he stopped taking the medicine; also the dispensary asked him for the test results and he couldn't go to the hospital to get them, so he couldn't get the medicine

Patient 138:
- 40 years old, male, farmer, Hindu, secondary pass, Nargol district, around 300 km away; left drinking 2 years back and left smoking 2 months back
- 2 years back completed 6 months of treatment and has been taking treatment for last 3 months (category II) relapse patient
- Has had to stop farming
- People kept their distance from him when he was first diagnosed, he did face social stigma

- **Patient 139:**
- 50 years old, female, housewife, Hindu, uneducated, left smoking 15 days ago
- Diagnosed with TB 15 days ago

Patient 140:
- 21 years old, female, housewife, Hindu, uneducated, no smoking, no alcohol
- TB for the last 5-6 months
- Felt tense when she was first diagnosed
- She lives in a different room than everyone else with different clothing and separate utensils

Patient 141:
- 50 years old, housewife, uneducated, housewife, left smoking 1 year back, from Altar district
- TB for last 2 years; started treatment 1 year back and started 6 months treatment; she took it again for 4 months but had to stop because of some kind of infection; (patient appears to be experiencing psychosis… is rocking back and forth and biting her clothing, muttering things that no one seems to be responding to)
- Her family didn't know about this TB hospital, but came here when they found out about it from relatives

Patient 142:
- 40 years old, female, from Altar district, housewife, Hindu, tobacco-chewer

- 4 years back, began treatment; she completed 9 months treatment in a private hospital; she is back here and is not sure if she has TB again
- Did not face any social stigma, but had separated utensils

Patient 143:
- Patient has had TB for the last 2 months, was admitted 3 days ago
- 19 years old, male, occasional smoker, chews tobacco, farmer, higher secondary graduate
- Has faced social stigma, people in his family don't want to come near him

Patient 144:
- 47 year old male, Hindu, from Altar district, was laborer but unemployed now, uneducated, chewed tobacco
- Defaulted 3 years back after taking treatment for 3-4 months because his body was "over-heating", meaning he wasn't feeling well
- Has had TB for the last 3 years and was admitted one week ago
- No change socially

Patient 145:
- 45 years old, male, Hindu, from Bharatpur, stone-crusher, ex-smoker and ex-alcoholic 14 years back
- Relapse patient, was a non-DOTS patient before and received private treatment for 6 months
- Now, he is taking course for 8 months and 2 of his brothers already died from TB
- No reported stigma

Patient 146:
- 50 years old, male, Hindu, laborer, 9th standard graduate, from Bharatpur, smoker during his treatment
- Took TB medication for 6 months and 9 months and hasn't had TB for past 2 years, but is being tested now for possible diagnosis
- No social change, but has not been able to work since he has gotten TB

Patient 147:
- 35 years old, male, from nearby village in Jaipur, 8th class graduate, farmer, left smoking 7 years ago
- 6 years back, was a non-DOTS patient and completed treatment for 9 months; 1 year later, took treatment for 9 months, but relapsed
- Notes some social stigma; some people have kept their distance from him, but not immediate family members

Patient 148:
- 46 years old, Hindu, primary school graduate, male, from Dhalpur, stone-cutter, occasionally smoked during his treatment, but left smoking about 6-7 years ago
- 10 years back, had TB with silicosis, received treatment for 7 months from a private hospital in Madhya Pradesh
- Reported no change socially

Patient 149:
- 16 years old, male, Muslim, from Haryana, knows only Urdu, primary education, chews tobacco but left this 15 days back, iron-welder
- Started treatment 6 months back, but left after 5 months because he was not feeling well and he thought that the medicine wasn't working

- No change socially, but had to leave his job after getting TB

Patient 150:
- 36 years old, Hindu, male, laborer, primary education, 2 years back he was a smoker, from Jaipur
- 2 years back, non-DOTS, defaulted after 1.5 months, then non-DOTS treatment from private hospital for 3 months and had partial improvement; he stopped because he was feeling well
- He has been getting treatment at the TB Hospital for 4-5 months
- No change socially

Patient 151:
- 35 years old, male, Hindu, from nearby district, stone-cutter, primary school, smoker, but left 1 year back, occasional alcoholic, tobacco chewer
- Didn't have patient's records, so couldn't tell if case of silicate or not
- 6 months back, he knew he had TB and he started taking medication, but defaulted after 5 months because he still had a cough and he thought that is wasn't working; patient also has diabetes
- He had to leave his job when he got TB, but does not report any social changes

Patient 152:
- 35 years old, male, Hindu, from Karolin district (200 km away), farmer, secondary school, smoker and alcoholic; was smoking during his treatment
- Started treatment for TB 6 months ago, but it was very hot outside and he was over-heating so he left treatment after 1 month
- Reported no change socially

Patient 153:
- 30 years old, female, Hindu, housewife, from Jaipur, uneducated
- 3 years ago, took treatment for 6 months from this hospital, but she had breathing problems and took treatment again after relapse, but she is okay now; however, patient's left lung is destroyed completely
- No change in her ability to do work, no social changes

Patient 154:
- 22 years old, female, uneducated, Hindu, housewife, non-alcoholic, non-smoker
- 2 years back, was diagnosed with TB, defaulted from treatment after 3-4 months because she felt better and didn't need treatment; her lungs are very damaged
- Since last 8-9 months, she has been taking medicine regularly; she needs to now complete 2 years of treatment because she has another lung infection

Patient 155:
- 22 years old, female, Muslim, primary class, homemaker, non-smoker, non-alcoholic
- Had TB for past 3 years, but defaulted after 2-3 months one year back and after 2 months two years back; she left the medicine because of heavy breathing and side effects from the medicine "over-heating"; it was very hot at the time
- She has been treated for the past 10 days, but has strong side effects, like vomiting
- Has faced social stigma, people tend to keep their distance from her

Patient 156:
- 20 years old, female, Hindu, student, graduate first year, from Agra; there is a leather factory near home
- Was diagnosed with TB in 2013, started treatment in Jaipur and then was transferred to Uttar Pradesh; after 6 months of treatment, but didn't feel well after 1 month (doctor didn't know

whether this was TB or not, so he just treated her symptoms); her lungs are damaged, but she doesn't have TB now
- She had to leave her studies when she got TB; she faced heavy social changes with her extended family members, as they did not want to come near her

Patient 157:
- 17 years old, female, higher secondary pass, Hindu, she's a college student, from Haryana
- Has had TB for last 3 months, cannot go to school because of her TB
- 3 months back, she was getting treatment from a local hospital in Haryana and took treatment for 2 months, but wasn't feeling better so she thought that the medicine wasn't working and defaulted
- She has been here for the last 10 days and is being tested for drug-sensitivity
- No social changes, but disease has interrupted her studies

APPENDIX D

Chest and TB Hospital – Patients' Treatment Histories, MDR-TB Ward

Patient 158:
- 20 years back, took 18 months of DOTS treatment; 5 years back, 6 months of DOTS, non-DOTS 6 months later for 6 months; 3 months later, non-DOTS for 7 months, has improved
- Has been treated for MDR-TB for the last 4 months
- Has continued smoking during treatment

Patient 159:
- 2 years back, DOTS patient for 6 months, completed course; became symptomatic around 2 months ago and LPA shows that patient is now H and R resistant (MDR-TB)
- No addictive history
- Contact history – father expired from tuberculosis

Patient 160:
- LPA shows H and R resistance, has been category IV MDR-TB since 16/5/15; patient has a history of on and off non-DOTS treatment for 5 years prior
- Non-smoker and non-alcoholic

Patient 161:
- Case of XDR-TB, has been H and R resistant since 23/12/14; patient has been category V since 3/1/15
- Non-smoker and non-alcoholic

Patient 162:
- MDR-TB patient; around 1-1.5 years ago, was category I for 6 months and completed treatment; relapsed and pursed non-DOTS treatment for 7 months; became category IV on 13/10/15
- Non-smoker and non-alcoholic

Patient 163:
- 10 years back was on non-DOTS treatment for 5.5 months, but no improvement; non-DOTS for 1 year and then there was partial improvement; 5 years back, was category I and took 6 months of DOTS treatment, but was still sputum-positive; 1 year later, DOTS for 9 months, then non-DOTS; 3 years ago became category IV, MDR-TB and completed 2 year course now is XDR-TB and is on treatment
- Non-smoker and non-alcoholic

Patient 164:
- In July 2014, non-DOTS treatment for 9 months; February 2015, DOTS category II for 2.5 months, but defaulted because of pregnancy; on DOTS for MDR-TB since 28/8/15, LPA shows that patient is resistant to H and R
- Non-smoker, non-alcoholic

Patient 165:
- 6 years ago, non-DOTS for 6 months; 4 years ago, non-DOTS for 6 months; 4 years ago, non-DOTS for 6 months; 2 years ago, non-DOTS for 12 months; came into DOTS as category I patient, no improvement after 6 months; February 2015, category II for 7 months, non-DOTS for 20 days; now is on treatment again
- Non-smoker, non-alcoholic

Patient 166:
- MDR-TB patient; 1.5 years back, was category I, but defaulted after 2 months of treatment; took non-DOTS treatment for 4 months; took category II for 8 months and then non-DOTS again for 2 months; went to hospital and was found to be H and R resistant in LPA
- Smoker and alcoholic, but has quit for the past 1.5 years

Patient 167:
- MDR-PTB; 1 year back, was non-DOTS for 10 months, but no improvement; LPA on 3/11/15 showed that patient is resistant to R and I; patient has been categorized as category IV since 11/11/15
- Non-smoker, non-alcoholic

Patient 168:
- MDR-TB patient; 15 years back, took 9 months of completed treatment form the government; patient then was on private treatment, symptomatics, for the past 10 months; LPA showed that patient is H and R resistant
- Non-smoker, previously consumed alcohol
- Contact history – patient's brother had TB

Patient 169:
- MDR-TB patient; 3 years back had a history of ATT and took non-DOTS treatment for 6 months; last month, category II relapse patient for 1 month; LPA showed that patient is H and R resistant
- Smoker and alcoholic, but has quit for 3 years

Patient 170:
- MDR-TB; in 2013 was DOTS, category I, took for 6 months, improved; in 2014, was DOTS category II (relapse) for 9 months and improved; was found to be category IV, MDR-TB, ever since 18/7/15
- Smoker, but has quit for 4 years; alcoholic, has quit for 1 year

Patient 171:
- MDR-TB; 1.5-2 years back, took ATT, category I DOTS for 6 months; then took non-DOTS for 6 months, but no improvement; then consulted doctor and LPA showed that patient was H and R resistant
- Non-smoker, non-alcoholic

Patient 172:
- MDR-TB; 1.5 years back, non-DOTS for 5 months, but no improvement; then took DOTS for 4 months as category I, but defaulted due to intolerance and side effects; patient has been on category II treatment for the last 3 months and is only R-resistant
- Non-smoker, non-alcoholic

Patient 173:
- MDR-TB; 18 years back, ATT, non-DOTS patient completed 9 months of treatment; 2 years back, category II, relapse, took treatment from this hospital for 8 months; non-DOTS for the past 2 months; LPA shows H and R resistance
- Smoker and alcoholic, quit 3 months back

Patient 174:

- MDR-TB; took ATT for one year back with DOTS, category I, completed 6 months of treatment; became symptomatic the past month; LPA shows that patient is now H and R resistant
- Ex-smoker and ex-alcoholic, has quit for past 2 years

Glossary of Terms

PTB – pulmonary tuberculosis
EPTB – extra-pulmonary tuberculosis
COPD – chronic obstructive pulmonary disorder
LPA – line probe assay

DOTS Categories of Patients[75]

Category I: fresh case of tuberculosis; treatment is 4 months of HRZE chemotherapy drugs (isoniazid, rifampicin, pyrazinamide, ethambutol), followed by 2 months of HR (isoniazid, rifampicin)

Category II: defaulter, relapse, or failure; treatment is 2 months of HRZES (isoniazid, rifampicin, pyrazinamide, ethambutol, and streptomyacin), followed up 6 months of HRE (isoniazid, rifampicin, ethambutol)

Category IV: MDR-TB; treatment is more complicated, often customized for patient, 8-9 months

Category V: XDR-TB; treatment complicated and customized for 2 years

[75] Dr. Sahil Patel, Resident at Chest and TB Hospital.

APPENDIX E

Interview Questionnaires

Interview Questions for Patients

1.) Age? Sex? Occupation, Religion? Education? Migrant? Smoker? Alcoholic?
2.) What was your diagnosis?
3.) What is your treatment history?
4.) If you defaulted, why was this?
5.) How was the important of treatment adherence and the disease itself explained?
6.) Exactly how long have you taken ATT; have there been any complications?
7.) Has your ability to work or study changed since you have gotten TB?
8.) Has your social life changed in any way since you have been diagnosed?

Interview Questions for TB Doctor/ Medical Officer

1.) What demographic patterns have you seen among TB and MDR-TB patients?
2.) In your practice, which population(s) have you observed to be the most "at-risk" for TB?
3.) What social factors do you believe particularly put them at risk?
4.) In your observations, how have doctors explained the importance of treatment adherence to their patients?
5.) In your experience, have most patients adhered to their treatment?
6.) Do you see any patterns among demographics of "drop-outs" from the DOTS program?
7.) What do you believe are the most common factors for why they drop out of treatment?
8.) In your experience, what is a typical treatment history like for MDR-TB patients?
9.) What has the government done through RNTCP to address these "at-risk" groups?
10.) How effective have these measures been in practice?
11.) What do you believe has been the biggest mark of success regarding TB treatment policy and RNCTP?
12.) What do you think needs to be the most improved in RNTCP?

Interview Questions for HIV/AIDS, Migrant Experts

1.) Could you please tell me a little bit more about your specialization and the population that you focus on?
2.) In your experience, how many HIV/AIDS patients are also infected with TB at some point?
3.) What demographic patterns have you seen among HIV-TB co-infected patients?
4.) Which social determinants do you believe put people at risk for co-infection?
5.) If it does, how do you think that the stigma that these patients face influences their health outcome?
6.) There is speculation that sometimes ART is not compatible with TB medication; if this is the case, how is it addressed?
7.) What kinds of patterns of drug-resistance have you seen among TB patients, both co-infected with HIV/AIDS and not?
8.) Which policies from RNTCP specifically address HIV/AIDS co-infected patients?
9.) How successful do you think these have been?

Interview Questions for Lab Technician at TB Hospital

1.) What exact kind of lab work do you do at the hospital here?
2.) So, how often do you see people who did not previously know that they were HIV positive, but found out after being tested here – in a month?

3.) How many cases does she usually cover per month?
4.) Once a patient tests positive, what is the next step?
5.) I realize that sometimes when patients are diagnosed with a co-infection of HIV and TB, that sometimes they cannot take both medications at the same time – what is typically done in terms of treatment with these kinds of cases?
6.) Have you observed any commonalities among the social characteristics of TB patients, generally speaking?
7.) Are there many cases of co-infection with TB and silicosis?
8.) Have you noticed any common characteristics among patients who have relapsed or defaulted from treatment?

Interview Questions for TB Counselor

1.) What specifically is your role with these patients?
2.) What have you found are some of their biggest concerns when they are first diagnosed with tuberculosis?
3.) How do you counsel these patients, regarding these concerns?
4.) Out of the patients that you counsel, are there any common characteristics that you see among them – any specific occupation, religion, caste, age, education level?
5.) In this area, if at all, how do you think the stigma that patients may face affects their treatment adherence and their likelihood to default from treatment?
6.) How are some patients able to overcome the stigma and mental issues that they may face?
7.) Have you observed any specific demographics that are common among patients who default?
8.) Do you counsel many MDR-TB patients? If it is different, could you please explain how this experience differs from working with drug-sensitive TB patients?

Interview Questions for RNTCP Representative

1.) How does policy address "at-risk" groups like single seasonal migrants who may be at risk for HIV-TB co-infection?
2.) How are these migrants tracked to make sure that they follow up with their treatment if they move from one district or state to another?
3.) What is currently being done to address the issues of silicosis and its strong association with tuberculosis? I understand that there is a review board that compensates silicosis patients?
4.) Is there any policy under RNTCP that addresses smokers as an "at-risk" group? If not, what other government schemes are trying to reduce the prevalence of smoking in Rajasthan?
5.) What are the major components of DOTS-Plus that are intended to tackle emerging issues with MDR-TB?
6.) How does RNTCP plan, in the future, to address issues pertaining to treatment adherence that may be contributing to increased drug resistance? For example, lack of knowledge and health education of patients?
7.) What do you think has had the biggest effect on the drastically improved rates of treatment in recent years?
8.) What is the biggest change that you would like to see that you think will further improve TB treatment and coverage in India?

Bibliography

Primary Sources

Abhishek Narang, microbiologist and HIV/AIDS expert at Directorate of Health and Family Welfare. (2015, November 14th). Personal interview.

Dr. Anil Gupta, Medical officer at Chest and TB Hospital. (2015, November 28th). Personal interview.

Dr. Nirav Banerjee, WHO representative at State TB Cell, Directorate of Health and Family Welfare, Rajasthan. (2015, December 2nd). Personal interview.

Dr. Rajesh Meenan, Resident at Chest and TB Hospital. (2015, November 20th). Personal interview.

Dr. Sahil Patel, Resident at Chest and TB Hospital. (2015, November 19th). Personal interview.

Dr. Sajan Singh, Chest and TB Hospital. (2015, November 25th). Personal interview.

In-patient Records, TB Wards. Rep. Jaipur: Chest and TB Hospital, 2015. Print.

Interview with TB patients, Chest and TB Hospital. (2015, November 24th & 28th). Personal interview with translator assistance.

Mrs. Kareena Jain, lab technician at Chest and TB Hospital. (2015, November 19th). Personal interview with translator assistance.

Mrs. Priya Mody, TB Counselor at Chest and TB Hospital. (2015, November 21st). Personal interview with translator assistance.

Nimal Kapoor, Migrant Expert at RSACS. (2015, November 19th). Personal interview.

Registered TB Patients; TB Counselor's Registrar. Rep. Jaipur: Chest and TB Hospital, 2015. Print.

Secondary Sources

2015 Global Tuberculosis Report. Rep. no. 978 92 4 156505 9. World Health Organization, 2015. Web.16 Nov. 2015. <http://apps.who.int/iris/bitstream/10665/191102/1/9789241565059_eng.pdf?ua=1>.

Ahlburg, Dennis A. *The Economic Impacts of Tuberculosis*. Amsterdam: Stop TB Initiative, 2000. Print.

"Country and Regional Data on Diabetes." *Diabetes Programme - WHO*. World Health Organization, 2015. Web. 29 Nov. 2015. <http://www.who.int/diabetes/facts/world_figures/en/>.

Gambhir, Harvir S., Rajeev M. Kaushik, Reshma Kaushik, and Girish Sindhwani. "Tobacco Smoking associated Risk for Tuberculosis: A Case-control Study." *International Health* (2010): n. pag. *Oxford Journals*. Web. 25 Nov. 2015. <http://inthealth.oxfordjournals.org/content/2/3/216.abstract>.

Hazarika, Basanta, Dr. "Silicosis and Silicotuberculosis." *Department of Pulmonary Medicine, PGIMER,*

Chandigarh. Web. 22 Nov. 2015. <http://www.indiachest.org/teaching_material/Silicosis%20and%20silicotuberculosis.pdf>.

Jayakrishnan, Thayyil, Bina Thomas, Bhaskar Rao, and Biju George. "Occupational Health Problems of Construction Workers in India." *International Journal of Medicine and Public Health* 3.4 (2013): 225-29. *PubMed*. Web. 27 Nov. 2015. <http://www.ijmedph.org/article.asp?issn=2230 8598;year=2013;volume=3;issue=4;spage=225;epage=229;aulast=Jayakrishnan>.

Kumar, Dhirendra, L.P. Singh, Barun Kanjilal, and Jatinder Bir Singh. *TBC India*. Rep. Indian Institute of Health Management Research, Nov. 2003. Web. 29 Nov. 2015. <http://tbcindia.nic.in/pdfs/Accessibility%20and%20Utilisation%20of%20RNTCP%20Services%2 y%2SC-ST%20Population%20-%20IIHMR.pdf>.

Nair, Nani, Fraser Wares, and Suva and Sahu. "Tuberculosis in the WHO South-East Asia Region." *Bulletin of WHO*. World Health Organization, Mar. 2010. Web. 24 Nov. 2015. <http://www.who.int/bulletin/volumes/88/3/09-073874/en/>.

National AIDS Control Organization. *HIV Sentinel Surveillance 2010-2011: A Technical Brief*. Rep. New Delhi: Ministry of Health & Family Welfare, Government of India, 2012. Print.

Oxlade, Olivia, and Megan Murray. "Tuberculosis and Poverty: Why Are the Poor at Greater Risk in India?" *US National Library of Medicine - National Institutes of Health* (2012): n. pag. *NCBI*. Web. 30 Nov. 2015. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3501509/>.

Phalte, Deepak B., Girish A. Purushottam, and Jayant D. Deshpande. "Prevalence of Pulmonary Tuberculosis Among HIV Positive Patients Attending Antiretroviral Therapy Clinic." *US National Library of Medicine - National Institutes of Health* (2012): n. pag. *NCBI*. Web. 26 Nov. 2015. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3731868/>.

Sharma, Surendra K., and Alladi Mohan. "Multidrug-Resistant Tuberculosis*: A Menace That Threatens To Destabilize Tuberculosis Control." *Chest Journal*. American College of Chest Physicians, July 2006. Web. 1 Nov. 2015. <http://journal.publications.chestnet.org/article.aspx?articleid=1084552&issueno=1&rss1>.

Singh, Akansha, and Laishram Ladusingh. "Prevalence and Determinants of Tobacco Use in India: Evidence from Recent Global Adult Tobacco Survey Data." *NCBI*. US National Library of Medicine: National Institutes of Health, 4 Dec. 2014. Web. 25 Nov. 2015. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4256395/>.

TB India 2014 - Revised National TB Control Programme - Annual Status Report. Rep. New Delhi: Central TB Division, Directorate General of Health Services, Ministry of Health and Family Welfare, 2014. Print.

"Tuberculosis (TB)." *World Health Organization - Media Centre*. World Health Organization, Oct. 2015. Web. 16 Nov. 2015. <http://www.who.int/mediacentre/factsheets/fs104/en/>.

"Tuberculosis and Diabetes." *Diabetes and Endocrinology*. The Lancet, 4 Sept. 2014. Web. 29 Nov. 2015. <http://www.thelancet.com/series/tuberculosis-and-diabetes>.