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A Silent Killer of India's Women: Investigating the Barriers To Adequate Tuberculosis Treatment and Diagnosis for Women in Bhopal, Madhya Pradesh

Evonne McArthur
SIT Study Abroad

A SILENT KILLER OF INDIA'S WOMEN:
INVESTIGATING THE BARRIERS TO ADEQUATE TUBERCULOSIS TREATMENT AND DIAGNOSIS FOR WOMEN IN BHOPAL, MADHYA PRADESH

Evonne McArthur
Academic Director: Dr. Azim Khan
Study Advisor: Dr. Surya Bali, All India Institute of Medical Sciences Bhopal
SIT Study Abroad
India Health and Human Rights Program
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GLOSSARY OF ABREVIATIONS AND ACRONYMS

AIIMS	All India Institute of Medical Science
DOTS	Directly Observed Treatment Short-Course
DMC	Designated microscopy Centre
DTC	District TB Centre
DTO	District TB Officer
HIV	Human immunodeficiency virus
MDGs	Millennium Development Goals
MDR-TB	Multidrug-resistant TB
MP	Madhya Pradesh
NGO	Non-governmental Organization
NSP	New smear positive
OPD	Out-patient Department
RNTCP	Revised National Tuberculosis Control Programme
TB	Tuberculosis
TU	Tuberculosis Unit
UN	United Nations
WHO	World Health Organization
XDR-TB	Extensively drug-resistant TB

1 INTRODUCTION

Nearly 20 years ago, the World Health Organization declared tuberculosis as a global public health emergency, yet today TB still remains a major global health challenge. It is estimated that during 2012 8.6 million were infected with TB and 1.3 million died from the disease (WHO, 2013). Globally, more than one third of the population is infected with TB and, after HIV/AIDS, TB is the greatest killer world-wide due to a single infectious agent. 95 percent of the global TB burden lies within low and middle-income countries and among the 22 countries determined to be high epidemiological burden countries, India ranks as number one (WHO, 2013).

Tuberculosis is an infectious bacterial disease caused by the inhalation of aerosolized respiratory droplets containing various strains of mycobacteria, primarily *Mycobacterium tuberculosis* (Beltz, 2011). Most TB infections are latent, asymptomatic, and non-communicable; however, in approximately ten percent of cases, latent TB can progress into the active disease (Central TB Division, 2005). There are many risk factors for active TB including HIV, tobacco smoking, alcoholism, and malnutrition—all of which suppress the immune system's response, making it more susceptible to infection (Singh, 2013).TB may infect any part of the body but it most commonly occurs in the lungs. Symptoms include persistent cough, weight loss, fever, and fatigue among other symptoms. Through strict compliance to a six to eight month rigorous course of antibiotic drugs, TB can be treated and cured; however, in some cases the bacterial strains are multidrug resistant leading to MDR-TB or XDR-TB (Central TB Division, 2005). After a few months of treatment a patient may seem symptom-free. But premature discontinuation of treatment, inadequate adherence to treatment, or improperly given treatment can lead to acquired drug resistance, making it a global public health concern (Beltz, 2011). In 2012, 450,000 patients were diagnosed with MDR-TB and 170,000 died due to it, although it is

estimated that in 2012 less than one in four patients infected with MDR-TB were detected (WHO, 2013).

The sixth goal of the United Nation's (UN) Millennium Development Goals (MDG) includes a 2015 target to reduce global TB burden by 50% from the 1990 levels (WHO, 2013). While the mortality rate has decreased significantly and many programs have been put into place to control the spread of TB, the decline in incidence rate has stagnated (Lonnroth, Jaramillo, Williams, Dye, & Raviglione, 2009). The current TB control strategy is primarily based on medical interventions; however, TB is a social disease and many other factors play a role in the prevalence and spread of TB, especially in developing countries. Although curable, TB has managed to persist for over 4,000 years and kill more than a billion humans. In order to meet the 2015 UN MDGs and eventually eradicate TB, the critical non-biological barriers to eradication must be confronted (Singh, 2013).

1.1 Women and TB

Historically TB has been viewed as a man's disease and although more men are diagnosed with TB, a higher proportion of women die from TB. It is the third biggest killer of women of reproductive age from 15-44 and more women die from TB yearly than all causes of maternal mortality combined (WHO, 2013; WHO, 2001).

There are many reasons why women are at great risk. The burden of stigma is much higher on women. In many areas women are much less independent and mobile than men and are thus less likely to seek treatment, receive diagnosis, adhere to treatment, and have a successful outcome without financial and travel support of family members (S. Ahuja, personal interview, October 8, 2013). Women are also more likely to be exposed to biomass fuels in small spaces for

cooking and are at greater risk of being malnourished and immuno-compromised, which increases susceptibility for an active infection (ACTION, 2010).

Additionally, doctors have been shown to exhibit a gender bias in the diagnostic process due to the view of TB as a man's disease. In Vietnam, when women had the same symptoms as men, they were less likely to receive a sputum test when at a medical facility (ACTION, 2010). In Pakistan, a greater proportion of women received false negative sputum tests due to diagnostic error and because women did not know how to give a proper sputum sample (ACTION, 2010).

The World Health Organization and International Union Against Tuberculosis and Lung Disease cites a need for literature review and field visits in order to study the gender differentials in TB because "research is lacking to explain the impact of gender inequalities in access to care on reported sex ratios for TB"; however, very minimal reports on barriers to adequate TB care for women in India have been produced (Uplekar et al., 2001). While greatly needed, no gender-sensitive or gender-specific approach has been developed or proposed to address the disparities and challenges that women face with regards to TB treatment or diagnosis.

1.2 Field Study Objectives, Questions, and Purpose

Because of the lack of current knowledge and apparent need, exploring these barriers and their effects is critical. The question that this investigation seeks to explore is: What are the major factors and barriers that prevent women from receiving prompt and adequate TB care and diagnosis in Urban Bhopal, Madhya Pradesh? Additionally, how have these barriers influenced diagnosis, compliance, drop-out, and success rates in the existing program within the last year?

Effective TB control is categorized by the many steps illustrated in Figure 1 and "gender may influence each of these [steps]" (Uplekar et al., 2001). This study aims to broadly examine

barriers throughout the whole process of treatment and diagnosis, but also to specifically look at step two, help-seeking behaviours; step 4, diagnosis rates; step 5, provider treatment practice; step 6, adherence or patient treatment behaviour; and step 7, outcome of treatment in women versus men. This study will investigate four broad barriers at each of the aforementioned steps: socio-cultural, economic, accessibility, and knowledge.

Figure 1. Steps of Effective TB Control

The ultimate goal of this investigation, in conjunction with others, is to elucidate prominent barriers for care and diagnosis for women with TB and to propose a gender-sensitive methodology to address the inadequacy of care in India. Based on the findings presented here, research questions will be proposed for future study.

1.3 Field Study Methods

The study at present utilized a two-pronged approach to investigate the barriers at the steps of TB control previously mentioned. First, a quantitative informational analysis was used to understand the scope of the tuberculosis epidemic in Bhopal and characteristics of care and outcomes for women. Second, interviews and field work were used to help determine the barriers to care and diagnosis for affected women.

For the first part of the study, records from the RNTCP were obtained from the Bhopal DTC and DTO, Dr. Manoj Verma. The data acquired were from three of the four Bhopal-district TUs—Jawaharlal Nehru Hospital (JNH), Jai Prakash Hospital (JP), and Community Health Centre Berasia (Berasia)—for Quarter III of 2013. The records of interest included the

"Quarterly Report on New and Retreatment Cases of Tuberculosis" and "Quarterly Report on the Results of Treatment of Tuberculosis Patients Registered 13-15 Months Earlier". Additionally, all data from the AIIMS Bhopal DMC RNTCP Lab Register were recorded since the DMC's opening on February 15th, 2013. This data lists all patients who are referred or self-report as symptomatic for TB and receive a sputum sample, their gender, their age, their address, and whether or not they are ultimately diagnosed with TB. All data was aggregated and statistical analyses were conducted.

To determine the barriers to care and diagnosis, this study utilized semi-structured interviews of women who had either just been diagnosed with TB but had not begun treatment, women who were currently undergoing treatment, or women who had completed treatment. A total of 13 women were interviewed. To obtain an accurate and inclusive representation of the barriers faced by the women of urban Bhopal, a diverse group of women were interviewed. The women ranged from 18 to 65 and were of different faiths, marital statuses, literacy levels, occupations, socio-economic statuses. They also came from different treatment centres and locations of residence within Bhopal. Women were asked to be interviewed individually to ensure control and reduce any confounding factors on the women's responses. One woman requested that she be accompanied by her mother and another requested that her husband accompany her, though when the husband tried to interject or provide an answer, the question was directed back towards the woman to ensure her voice was the one heard. One patient's husband was interviewed because his wife did not feel well and one interview was conducted jointly—with a maternal grandmother who was currently undergoing treatment and her granddaughter who had completed treatment previously.

Additionally, RNTCP staff including the DTO, health professionals, DOTS providers, and NGO staff were interviewed to gain a more complete picture of the obstacles that the women face. They were also asked their views on the successes and failures of the RNTCP programme with regards to the diagnosis and treatment of women. Anonymized profiles of all patients are included in Appendix 1. To protect confidentiality all names of patients, doctors, and nurses have been replaced by a pseudonym. Names that had religious significance were renamed accordingly. All interviewees were read a form of consent in either Hindi or English and verbal consent was obtained. All interviews with the women patients were conducted at the OPD or hospital where they received their treatment with a staff member as a translator.

A questionnaire was prepared to investigate the four types of barriers: socio-cultural, economic, accessibility, and knowledge. For example, socio-cultural questions probed womens' traditional or spiritual medicine usage, family support system, perceived community view of TB, and feelings of discrimination or stigmatization; economic questions considered income source, profession, transportation methods, and food; accessibility questions determined distance and time to treatment, transportation methods, and challenges in receiving their care; and knowledge-related questions investigated current and pre-diagnosis views and knowledge about TB, how long it took to seek care after becoming symptomatic, reasons for waiting to seek care, reasons for deciding to seek care, and current information sources regarding TB.

Different questionnaires were used for other health professionals. In addition to asking about perceived barriers for the women, questions investigated other barriers such as drug supply availability, diagnostic instruments, diagnostic accuracy, budget, state support, human resources, counselling, and potential TB services that are specifically tailored for women or address women's needs. While questionnaires were used to ensure experimental control, a semi-

structured interview approach was taken to ensure applicable questions were being asked and additional follow-up questions could investigate previous answers in greater depth. General questionnaires for patients and the health providers are presented in Appendix 2.

1.4 Field Study Setting

This research project was conducted in Urban Bhopal, the capital of MP and sixteenth largest city in India. Conducting the project in a capital city allowed the researcher to interact with officials in the state TB cell, DTC, and multiple DOTS centres and hospitals. Additionally, Bhopal is highly urbanized with more than 80% of the population living in urban areas. Rates of TB transmission and infection are significantly higher than in more rural areas, and Bhopal continues to grow and urbanize (Jamia Millia Islamia University, 2008). Additionally, in 1984 Bhopal was the site of the world's worst industrial disaster when over 500,000 people were exposed to methyl isocyanate gas and other chemicals from the released by the Union Carbide India Limited (UCIL) pesticide plant. Due to this many of the victims' lungs are more "delicate and sensitive" and are therefore more susceptible to TB infection (M. Verma, personal interview, November 11, 2013).

In 2011, patients in Madhya Pradesh alone accounted for 6.00% of all of India's TB cases being treated by the RNTCP and 5.74% of the new smear positive patients diagnosed (TB Statistics for India, 2013). A previous study conducted in Chhattisgarh, a state formerly part of MP, found that 80% of women have moderate to severe under nutrition, negatively influencing the effectiveness of their TB treatment (Bhargava et al., 2013). This study illustrates that TB is not only a biological disease and suggests a need for further research on the barriers to proper TB care for women in this area. In addition to under nutrition, MP has historically some of the worst

socio-economic indicators, basic amenity indicators, and health indicators. In the *Baseline Survey of Bhopal District* conducted by the Ministry of Minority Affairs and Jamia Millia Islamia University, New Delhi (2008), it was noted that only 68.8 percent of households have safe drinking water, which is significantly less than India's average at 87.9 percent. Additionally, the female work participation rate is only 15.01 percent compared to India's 21.5 percent, and only 24.9 percent of children are fully vaccinated as compared to India's 43.5 percent.

Bhopal has four reporting TUs, 26 DMCs, and about 1126 DOTS centres (M. Verma, personal interview, November 11, 2013). For this study, quantitative data were used from three of the TUs and qualitative data from patients and providers at 3 DOTS centres—K. N. Katju Hospital, DTC, and AIIMS Bhopal—and one government-run Tuberculosis Hospital were also included. Figure 2 shows a map of these locations across Bhopal, except the Berasia TU as it is approximately 45 kilometers north of central Bhopal.

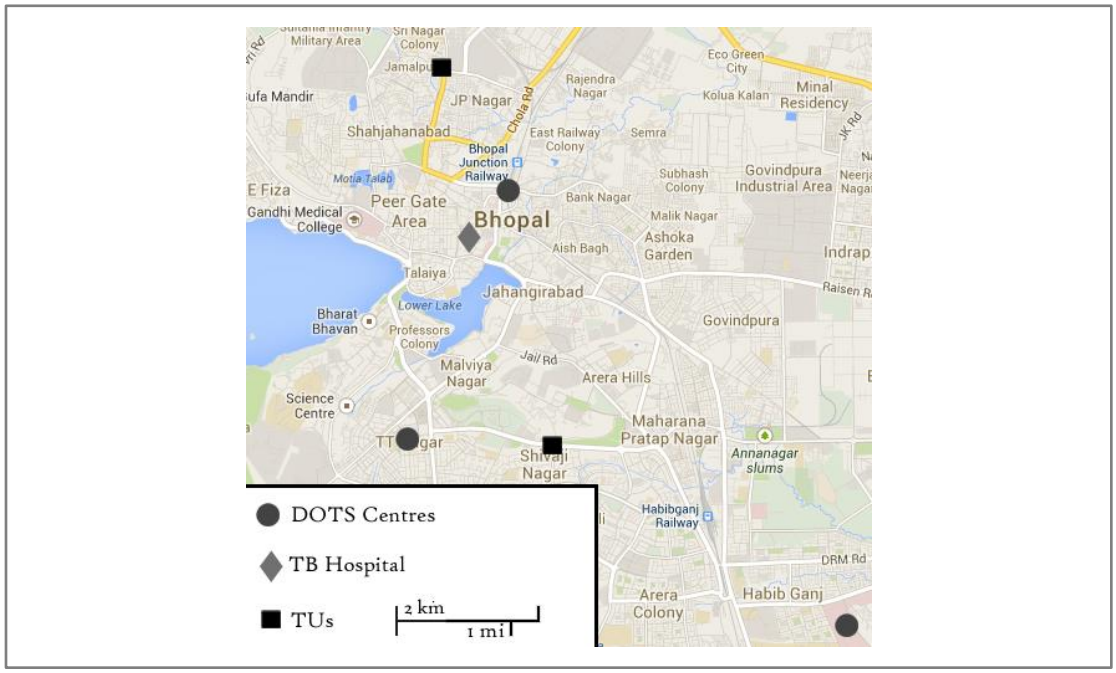

Figure 2. Centres of Data Collection for the Present Study

2 OVERVIEW OF TUBERCULOSIS IN INDIA

It is estimated that there are currently between 1.9 and 3.9 million cases of tuberculosis (TB) in India—making it the largest TB epidemic globally and accounting for almost 30% of the global burden (WHO, 2013). Even more alarmingly, the burden of MDR-TB is greatest in India and becoming more prevalent. Furthermore, India is one of only three countries where totally drug-resistant TB (TDR-TB) has been documented. (Kim, Shakow, Castro, Vande, & Farmer, 2013).

Women in India also face additional challenges and barriers to health care. Bhopal DTO, Dr. Manoj Verma, stated that the accessibility and ease of receiving TB treatment for women different than men "because in India their social status is different, their job responsibility is different, their value is society is different, their power in society is different." All of these factors affect rates of diagnosis and treatment success rates in India versus other countries (M. Verma, personal interview, November 11, 2013). Figure 3 illustrates the male to female ratios of NSP diagnoses over time for 42 countries from the WHO Global TB Report 2013's highest burden regions: countries from the Africa and the Western Pacific regions. Through the figure, it can be seen that India has one of the highest male to female NSP ratios through the duration of the RNTCP—from 2.6 to 2.2 males for every female diagnosed. While this could simply indicate a higher prevalence of men infected with TB than women, this is unlikely because women are "more likely to progress from infection to active disease." It is better interpreted as a failure to adequately diagnose or case-find women with TB due to some unknown barriers to be investigated (Kim et al., 2013).

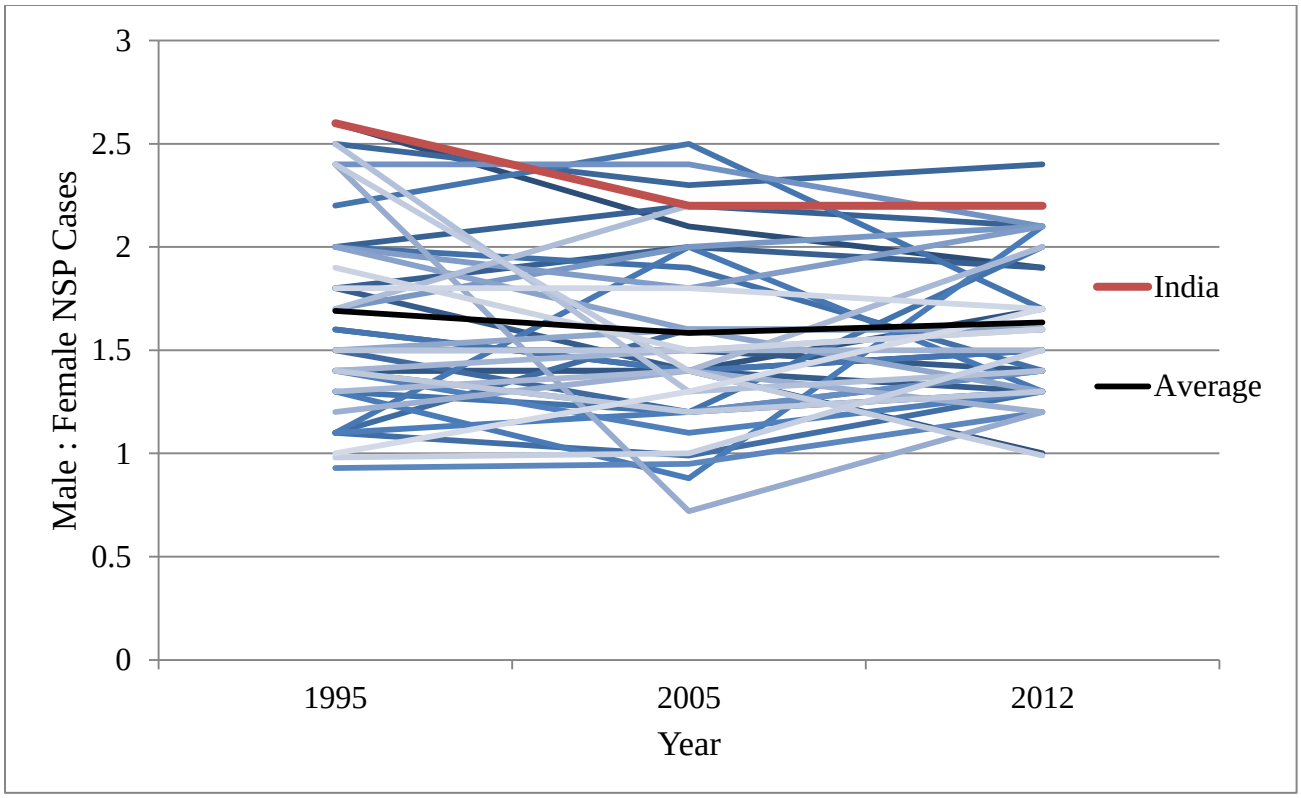

Figure 3. Male to Female Ratio of NSP Cases from 1995-2012 of 42 Countries

2.1 Revised National Tuberculosis Control Plan

In 1993, after the WHO declared TB a global public health emergency, the Government of India with the World Health Organization and Swedish International Development Agency (SIDA) developed and implemented the current TB control program in 1997 based on the recommended Directly Observed Short-course (DOTS) strategy (Verma, Pardeep, & Mehta, 2013). This program, the Revised National Tuberculosis Control Program (RNTCP), achieved coverage of all Indians in 2006 and focuses on objectives for increased detection and treatment success rates.

The primary tool for diagnosing TB is sputum smear microscopy which is inexpensive, simple, and has low inter-reader variation. If read correctly, at least 50 percent of new pulmonary

TB patients will appear smear positive (Central TB Division, 2005). A medical practitioner will screen patients and advise those who are symptomatic—a cough for three weeks or more—to undergo sputum smear examination at the DMC. Three sputum specimens are collected over two days, with one in the early morning (S. Patel, personal interview, November 29, 2013). The Technical and Operational Guidelines for Tuberculosis Control states that before a health worker collects the specimen, reasons for collection must be explained to the patient and sputum specimens should be read the same day. Depending on the examination finding, the smear is graded as either 3+, 2+, 1+, Scanty, or Negative. If two or more smears are positive, the patient is determined as NSP and anti-TB treatments are started; if one smear is positive, a chest X-ray is used as an additional diagnostic tool. When diagnosed the patient is to be "counselled and motivated to adhere to treatment as recommended […] told about TB, dosage schedule, duration of treatment, mode of transmission, precautions to be taken to prevent the spread, [and the] importance of directly observed treatment and its duration" (Central TB Division, 2005).

Patients are defined as either new (Category I); relapse, a patient who had previously been cured or completed treatment (Category II); or treatment after default, a patient who had taken treatment for one month or more but subsequently failed to take treatment for two months or more (Category II) (S. Patel, personal interview, November 29, 2013). RNTCP's goals for treatment are to decrease mortality and morbidity, minimize relapse, prevent development of drug resistance, and decrease transmission of infection. To achieve these goals and increase treatment adherence, treatment is provided three times a week under direct observation at a DOT provider at a peripheral health institution or DOTS centre. Category I patients undergo a six month regimen: two months of intensive phase and four months of continuation phase. Category II patients undergo an eight month regimen: two months of intensive phase plus Streptomycin,

one month of traditional intensive phase, and five months of continuation phase plus ethambutol (Central TB Division, 2005). The drugs are packaged in weekly blister packs and supplied in patient-wise boxes.

Treatment outcomes are classified as either *cured*, which means treatment was completed with two negative smear results including one at the end of treatment; *treatment completed*, completed treatment with negative smear at the end of intensive phase but none at the end of treatment; *died*, known to have died from any cause during treatment; *failure*, smear-positive five months or later; and *defaulted*, failed to take drugs for more than two months consecutively (Central TB Division, 2005).

3 GENDER DIFFERENTIALS IN TREATMENT AND DIAGNOSIS

To characterize the challenges that the women of Bhopal face with regards to effective TB control, a quantitative information-based analysis was done to uncover any gender differentials and inequities in help-seeking (Figure 1, Step 2), diagnosis rates (Figure 1, Step 4), and outcome of treatment in women versus men (Figure 1, Step 7).

3.1 Help-Seeking

From analysis of the AIIMS Bhopal DMC RNTCP Lab Register from Feburary 15th 2013 to November 20th 2013, it was determined that a total of 151 patients were referred by an AIIMS Bhopal physician or self-referred for TB symptoms and received a sputum test. The male to female ratio of those who received a sputum test was 2.35: 106 males and 45 females. The average age of all patients was 37.12: 37.6 for males and 35.9 for females. Through utilization of

a 1-tailed T-test for analysis of significance in the age difference of symptomatic males versus females it was determined that approximately 29 percent of the time ($p = 0.29$), the age difference could be attributed to random variation and that this difference may not be significant. Although the mean ages were not necessarily significantly different, a Gaussian kernel density estimation (KDE) to non-parametrically approximate the probability density function of the ages of male versus female patients identified as symptomatic was created given the available sample.

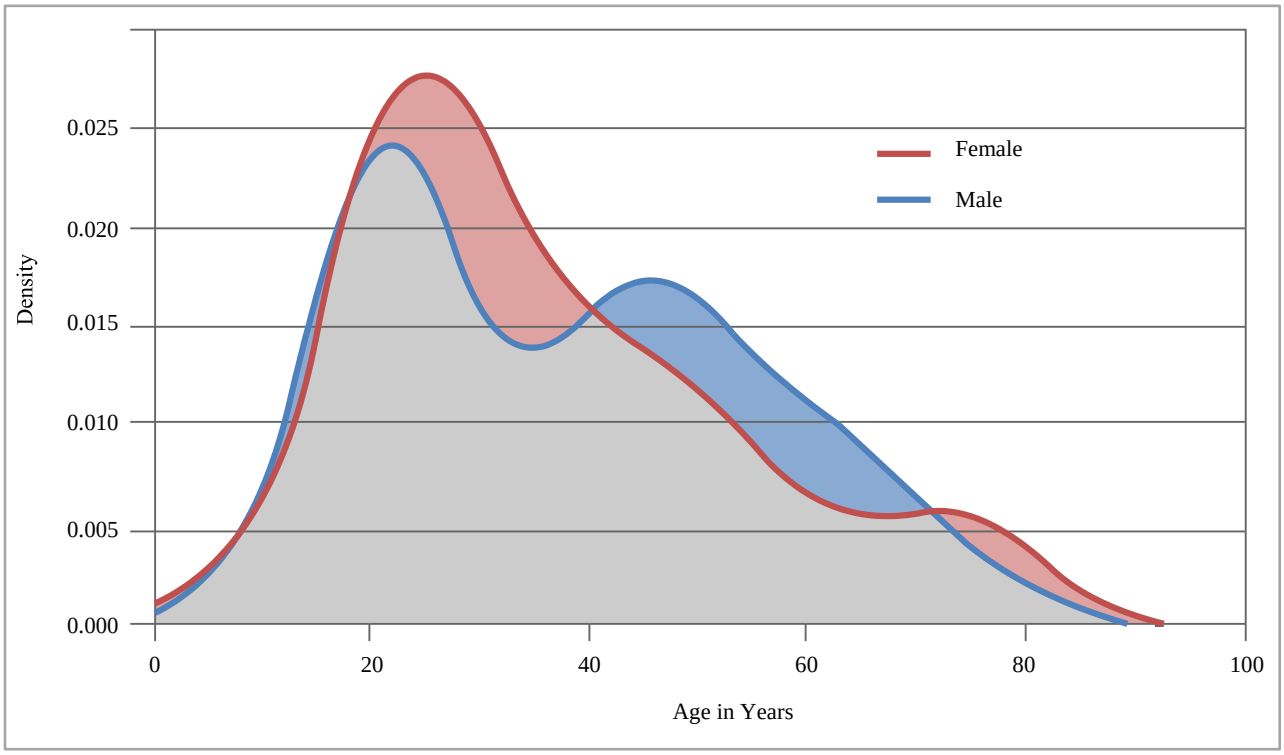

Figure 4. KDE Probability Density Function of Men vs. Women who are identified as symptomatic

Through the KDE in Figure 4, it is apparent that a disproportionately larger fraction of women being identified as symptomatic for TB are under 40 years old or over 70, though the sample size for patients over 70 is small. Conversely, the largest proportion of men being identified as symptomatic is from 30 to 70, though a large proportion also comes from men aged

10 to 30. This suggests that while men were identified and tested for TB at all ages almost equally, except for a dip at 30 to 35, most women were identified and tested at younger ages.

All sputum samples produced by male patients were conclusive; however, one female patient was required to do a repeat set of samples due to inconclusive results the first time. This delays treatment and could indicate that women are not given sufficient instruction on how to provide an adequate sputum sample or too embarrassed to ask as found in a previous study (ACTION, 2010).

Most patients who receive a sputum smear examination from a DMC are referred there from another physician. For example, a patient visits the AIIMS OPD where the physician notes TB-like symptoms and refers them to the DMC although the patient had not initially suspected TB or come for a sputum smear examination. However, some patients are aware of the symptoms of TB and directly self-refer themselves for TB diagnostics to the DMC. From the AIIMS DMC sample, 11 males self-reported TB symptoms; however, only 2 females did. This could indicate that females are less aware of the TB symptoms or are more likely to deny that symptoms are related to TB and intend to seek other treatment or medications rather than receive a TB diagnosis. These barriers to help-seeking behaviours will be explored through the second part of the study: personal interviews.

3.2 Diagnosis

After one seeks help and is able to access a health facility, the next step is obtaining a diagnosis. To determine the proportion of males versus females who are diagnosed in Bhopal, the RNTCP "Quarterly Report on New and Retreatment Cases of Tuberculosis" was analysed from 3 Bhopal TUs with sample size of 261. Figure 5a shows the number of male versus female

NSP pulmonary TB diagnoses for quarter III of 2013 and figure 5b shows the number of male versus female diagnosed relapse retreatment TB cases.

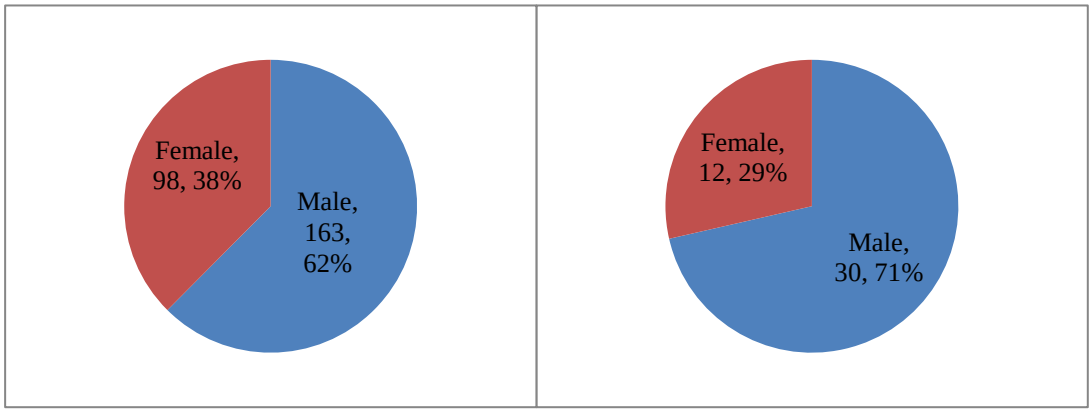

Figure 5. Male versus Female Diagnoses for (a) NSP Pulmonary TB (b) Relapse Retreatment Cases

Because the distribution of ages for those who presented symptomatic of TB for males and females was different as described in section 3.1, the distribution of NSP cases by age and gender was created. Since the age data was provided in discrete bins rather than as a continuous set, a histogram rather than KDE was used. Figure 6 shows the absolute number of NSP pulmonary TB cases in a stacked histogram of men and women. Figure 7 shows the relative proportion of female to male NSP Pulmonary TB cases for each age bin.

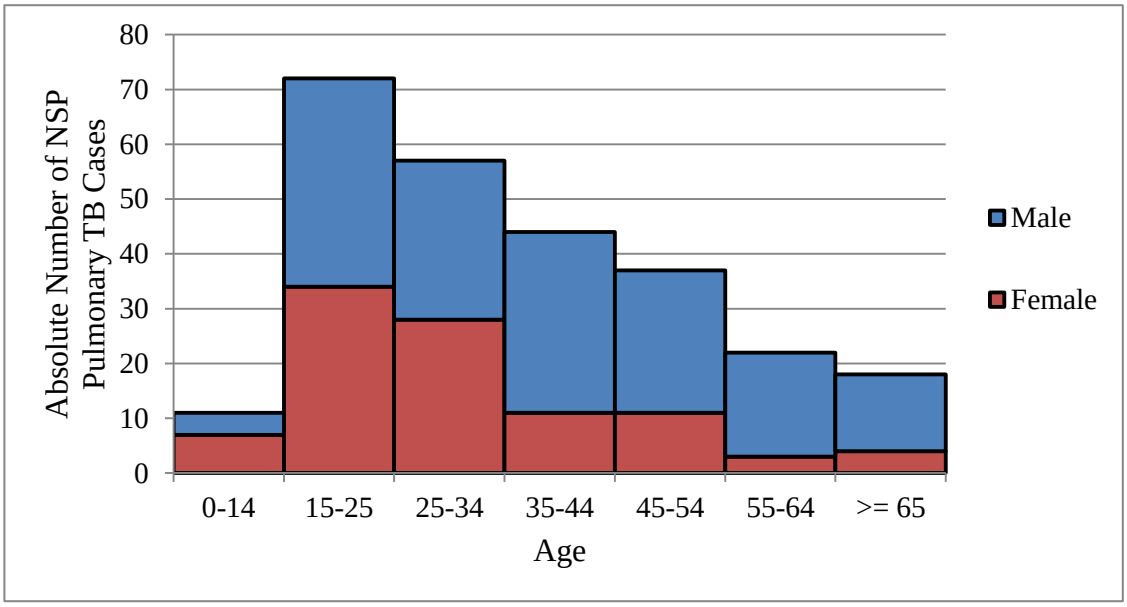

Figure 6. Stacked Histogram of the Absolute Number of NSP pulmonary TB cases

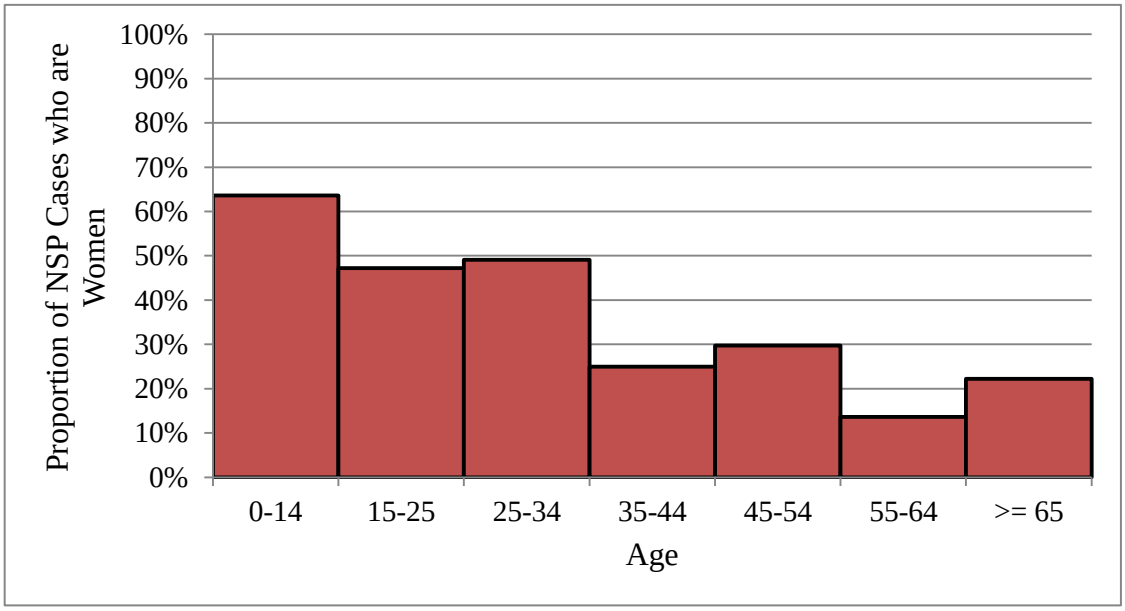

Figure 7. Relative proportion of female to male NSP Pulmonary TB cases for each age bin

Through these figures it is apparent that as the population grows older, a greater proportion of those who are diagnosed are male. Up to age 14, over 65 percent of those diagnosed are women; however at ages greater than 55, less than 20 percent of those diagnosed

are women. A Chi-square contingency table analysis concluded that the distributions of the ages of NSP Pulmonary TB patients in men versus women are significantly different ($p < 0.001$).

3.3 Outcomes

Finally, the outcome of patients diagnosed from 13-15 months ago was examined. Because the outcome "death" is encompasses death from any cause and is greatly influenced by age, the outcome category "death" was omitted from this study to reduce confounding factors because a larger proportion of female patients are younger and because the sampling of those who died during treatment is small.

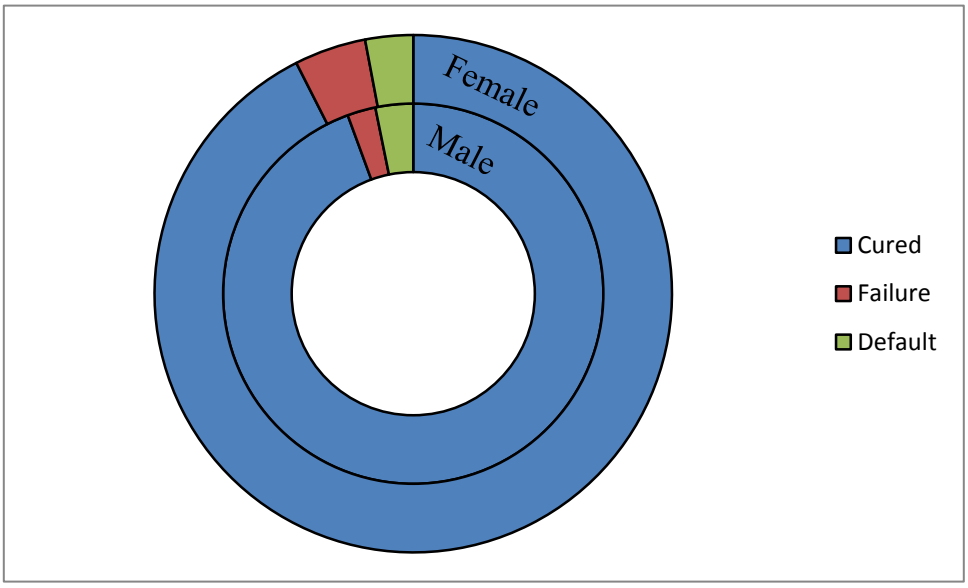

Figure 8. Treatment Outcome of Female and Male NSP Pulmonary TB Patients

Figure 8 shows the outcome results of treatment for 204 NSP Pulmonary TB patients: 135 male and 69 female. This figure shows that a slightly lower percentage of women were cured after treatment. Treatment failure can occur for many reasons: biological resistance, acquired resistance from intermittent breaks in treatment, intermittent breaks in treatment less

than two months but long enough for the treatment to be rendered ineffective, or poor environment or nutrition which has previously shown to decrease efficacy of treatment. For these reasons, it is important to explore the underlying social factors which decrease women's ability to have successful outcomes during TB treatment (Bhargava et al., 2013).

3.4 Discussion

Through the analyses of the available RNTCP records, many interesting trends have been uncovered and new questions brought to light. First, a larger proportion of women who are symptomatic and are diagnosed with TB are younger. It is hard to determine whether or not the skewed ratio of men being treated for TB to women being treated is representative of the actual ratio of active TB infections in Bhopal or a result of the additional barriers women face in receiving diagnosis, which would mean that a larger proportion of women is going undiagnosed. Many points of evidence suggest the later. First, many fewer women than men self-reported TB symptoms, creating a large barrier for diagnosis. Additionally, the gender ratio for symptomatic patients at the AIIMS Bhopal DMC was 2.35 men to women, whereas the ratio of those diagnosed with active TB from the 3 Bhopal TUs was 1.66 men to women. This suggests that a smaller proportion of women than men who actually have TB are exhibiting help-seeking behaviour for their TB-like symptoms.

Even once receiving treatment, women are less likely to be cured and more likely for treatment to fail. Although treatment for women is more likely to fail, 2.5 men for every woman are diagnosed and begin treatment, as a relapse retreatment cases shown in Figure 5b. This is alarming and reasons for the disparity in help-seeking behaviour and treatment outcome was further explored using field work and presented in the following section.

4 INVESTIGATION OF BARRIERS FOR WOMEN

4.1 Socio-cultural

In India, unlike many developed countries where the prevalence of TB is lower, the social role of women is very distinct from that of men, which creates a distinct set of social challenges that women face in receiving TB treatment and diagnosis. Seema, a nurse at the Bhopal TB Hospital, concluded that TB is harder for women because India is a male-dominated society and for that reason society doesn't accept women with TB, which leaves women stigmatized and ashamed (Seema, personal interview, November 13, 2013). Dr. Manoj Verma echoed these sentiments when he claimed that one of the biggest social barriers to TB treatment is the stigma that women face. He stated that the stigma definitely still exists in Bhopal and that this stigma "makes women hesitate to come to the TB Centre [for diagnosis], hesitate to come to the DOTS centre [for treatment], and hesitate to disclose their complaints of cough and weight loss" (M. Verma, personal interview, November 11, 2013).

Stigma is a phenomenon where a particular characteristic is identified as negative causing the individual to be targeted as undesirable. This stigma is formed and shaped by "institutional and community norms and interpersonal attitudes," which can lead to shame, guilt, withdrawal, exclusion, and risky-behaviours (Heijnders & Van Der Mejj, 2006). TB carries a heavy multi-faceted stigma, especially for women, which can lead to severe isolation in certain cases.

Married women may be left by their husband and children or face harassment from family members and in-laws; unmarried women may be unable to find a partner; tenants may be thrown out of their accommodations; employees are at risk for losing their jobs; and children can

be deprived of their right to education if they or a parent are affected (S. Ahuja, personal interview, October 8, 2013; WHO, 2001). TB is also "linked to other disvalued characteristics" such as "malnutrition, poverty, being foreign-born, [and] low social class." It is also perceived as a marker for HIV positivity, due to the co-epidemic in certain areas and is also perceived as divine punishment for personal failings (Courtwright & Turner, 2010).

Of the 13 women interviewed, four openly admitted to feelings of shame, discrimination, or stigmatization by their community (Safa, Fariha, Pooja, Divya, personal interviews). Others were aware of the stigma and potential negative implications of sharing their diagnosis with their family or community. To avoid these potential complications and stigma, many hid their diagnosis and did not leave their house except for the days went they go for treatment. For example, one woman, Shruti, stated that she does not feel stigmatized; however she does not tell her neighbours or distant family members because she knows that they would think of her negatively, avoid her, and treat her differently (Shruti, personal interview, November 20, 2013). Another 20 year old woman, Preeya, who was diagnosed nine months ago and has since completed her treatment, stated that she did not inform anybody—none of her family members or neighbours—and walked two kilometres to the DOTS centre three times a week for six months to take her treatment. She isolated and distanced herself from her family, friends and neighbours in fear that everybody would "see her in a bad manner." Because nobody in the family knew about her diagnosis and no adequate precautions were taken, her maternal grandmother contracted TB and is now receiving treatment (Preeya, personal interview, November 21, 2013). Figure 9 shows the breakdown of the people to whom the TB patients interviewed disclosed their TB diagnosis. To examine how the age of the patient correlates with

the number of people they disclose their diagnosis to, a line chart depicting average age of patient's disclosure level is overlaid on the bar chart.

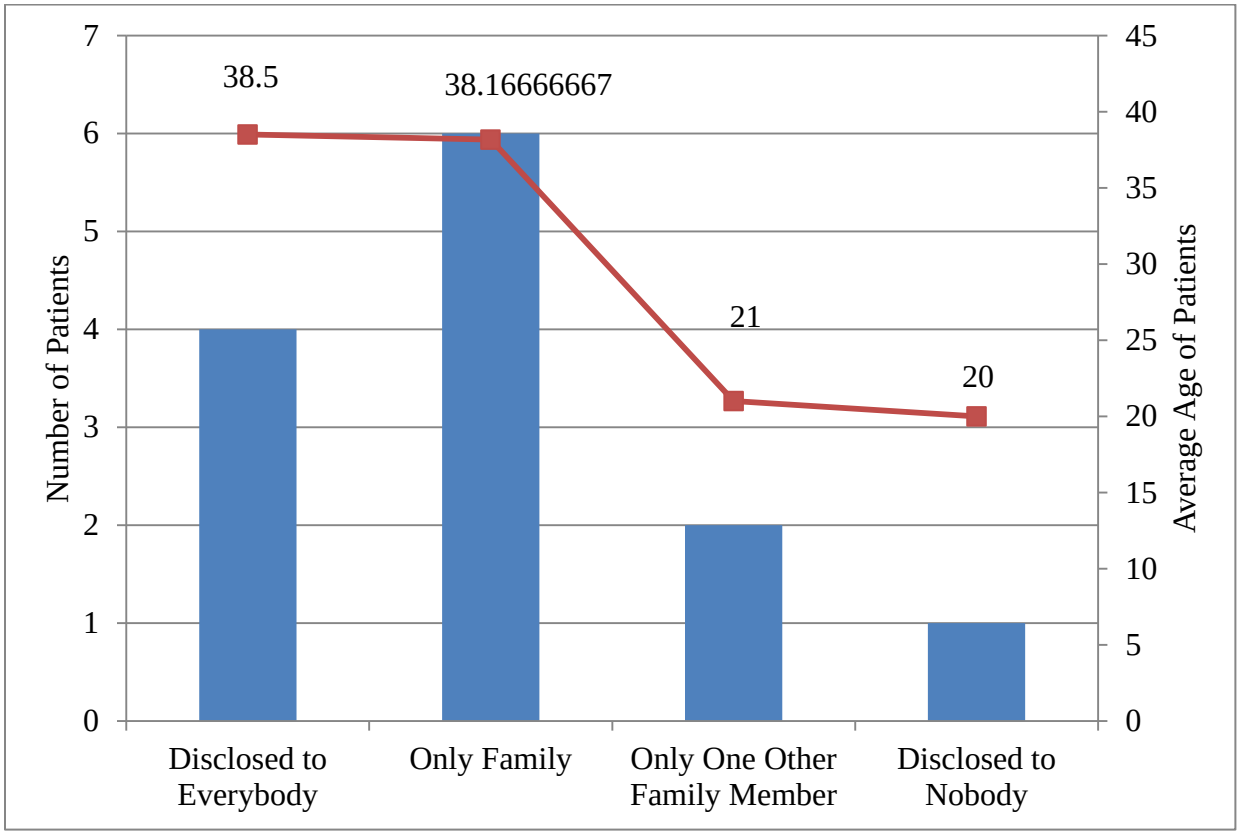

Figure 9. Disclosure of TB Diagnosis Plotted with Average Age of Patients

Although the sample size is small, Figure 9 shows that most patients disclosed their diagnosis to only family. Furthermore, the younger the patient, the more likely they were to hide their diagnosis and tell only one family member or nobody. If hiding diagnosis is viewed as an indicator of how seriously stigma is perceived, it may suggest that younger women in their early 20s feel the pressure of stigma and a need to hide their diagnosis more than older women do. One reason for this relates to another Indian cultural custom: the pressure for young women to get married. Marriage is one of the most important parts of a young woman's life and it is often viewed as a social and familial obligation (Mehta, 2005). DTO, Dr. Manoj Verma, explained that

in other countries like the United States "there is no criteria to reject for TB whereas in India if a family has two choices to either marry their son to somebody who had TB, even if they were cured, or never had TB, they will always choose somebody who has not had TB" (M. Verma, personal interview, November 11, 2013). One 22 year old woman interviewed, Disha, was diagnosed with TB one year ago, treated at a private clinic, but continually defaulted. Six months ago she was diagnosed with MDR-TB and was transferred to live in the Bhopal TB Hospital. Because she resides in the TB Hospital, her community has become aware of her diagnosis. When Disha was asked what the biggest change in her life post-diagnosis, she stated "I am not married." While she was not married before diagnosis at 21, Disha and her family expected that she would be married now, but knows that because her community knows about her TB diagnosis she has not been able to get married and may not marry in the future. Because of this, she feels as if she has no respect in the community and is financially insecure, as neither she nor her mother works. She did not mention her father (Disha, personal interview, November 13, 2013).

If a woman is already married, her husband may leave her or take away her kids in fear that TB will spread to the family or stigmatize the family as a whole; one study reported that each year over 100,000 women are rejected by their families (Directorate General of Health Services TB India, 2005). Of the married women interviewed here, one did not tell her husband but many others stated that their husbands were supportive. One woman, Gayatri, stated that her husband was supportive however they do not always live together and when the doctor told her that treatment was for six months, her husband insisted that she take the treatment for a year before returning and that their daughter should also take preventative treatment rather than

simply take precautionary measures (Gayatri, personal interview, November 12, 2013). The RNTCP provides prophylactic treatment for young children whose parents have been diagnosed with TB. This treatment has decreased the number of husbands who leave their wives, but does not address the underlying stigma and informational misunderstanding behind why they leave (S. Patel, personal interview, November 29, 2013). Some NGOs who work to eradicate TB, like Operation ASHA, have "camouflaged" DOTS centres in shops and temples or will provide medications to patients at home during the day when their husband are not home so that they do not have to worry about the consequences of their spouses knowing of the TB diagnosis; however, again, this does not address the underlying stigma (S. Ahuja, personal interview, October 8, 2013).

Another cultural barrier to diagnosis is the belief that TB is divine punishment, a spiritual disease, and that gods have cursed them with TB (Pooja, personal interview, November 18, 2013). For this reason, and to avoid being stigmatized by a TB diagnosis, many women "go to *jaadu tona*, black magic, or *sahdu babas*, holy men" (Seema, personal interview, November 13, 2013). Two of the women interviewed had utilized these forms of traditional healing prior to being so sick that they were forced to receive a TB diagnosis and treatment at a government hospital. One 40 year-old woman, Gayatri, had been symptomatic of TB for over two years and was receiving treatment from a saint and receiving *Jhaad Phoonk*, non-medical treatment used to treat ailments of the mind and spirit, before finally accepting treatment and a TB diagnosis (Gayatri, personal interview, November 12, 2013).

These forms of isolation and overwhelmingly negative perception consequent from stigma form large barriers to diagnosis, adherence to treatment, and successful outcomes. Not

only do the social-cultural barriers and stigma affect older, more traditional, and poorer families, but they also affect more upper-class, educated, and independent women. For example, Pooja, a 24 year-old software developer, graduate, and niece of a doctor, expressed feelings of stigma and shame (Pooja, personal interview, November 18, 2013). Additionally, five of the women interviewed expressed feelings of depression, isolation, and fear (Safa, Disha, Pooja, Divya, Preeya, personal interviews). To escape this discrimination, patients may ignore their symptoms, delay treatment seeking, or reject a diagnosis (WHO 2001). The increase in diagnostic delay in turn increases the risk of transmission to contacts (as it did from Preeya to her maternal grandmother) and negatively impacts the health and treatment success of the infected individual. Not only does the stigma affect diagnosis, but lack of a financial livelihood, travel assistance, or an adequate support system also greatly affect the compliance and success of treatment, which could lead to resistant strains of TB and death.

4.2 Economic

Previous studies have suggested that poverty is a large barrier to TB treatment (Gupta, Shenoy, Mukhopadhyay, Bairy, & Muralidharan, 2011); however, the Bhopal DTO ensured that all DOTS treatment, sputum and X-ray diagnostic tests, and stays at the government Bhopal TB Hospital are free to patients and covered by the government (M. Verma, personal interview, November 11, 2013). However, through data collected through the interview process, there were many other economic burdens and barriers to treatment expressed, especially for women, most of which were not visible at first.

Although the RNTCP provides free services as government hospitals, due to the perceived quality of care, travel distances, and perceived wait-times, many patients choose to

first seek assistance at private hospitals, where often they are required to pay much more for less adequate care or diagnoses. Seema (November 13, 2013), Bhopal TB Hospital nurse, expressed her views on the economic barriers patients face with regards to the private physicians:

> 90 percent of the patients here are below the poverty line yet they rely on the private sector. The Indian government is giving full support to eradicate TB from India, yet they [patients] prefer to first spend money in the private sector. But the private doctors just want more money; they diagnose wrongly and give another treatment. Then when the patient is conditioned to die, when money is over and gone, they refer to the TB Hospital and at that time the patient is in a condition where many times we can't do anything and they have given up all hope. TB can be cured with proper treatment and proper diet but at this point, all money is gone—money for even one meal a day is gone.

Dr. Manoj Verma and Dr. Rahul Kumar*, a Bhopal physician who refers symptomatic patients to the DMC, echoed this sentiment and emphasized the number of "quacks" that claim to be doctors in the Bhopal private sector (M. Verma, R. Kumar, personal interviews). One estimate suggests that more than half of TB patients bypass RNTCP services and are either untreated or treated in private sectors—which is a serious considering India's large TB burden. While 75 percent of doctors are based in private practice only 0.31 percent implement RNTCP and most are unregulated and have no access to information or TB-treatment training programmes (Verma et al., 2013).

Five of the 13 patients interviewed (38 percent) visited at least one and up to three private physicians before receiving their diagnosis at a government DMC. In the time that the patients

* Pseudonym

received treatment from the private physicians, which ranged from two months to two years, none of the private doctors gave a TB diagnosis.

Poverty has an established and direct link with TB: when one is in an area with poor sanitation, crowding, poor air circulation—all "factors associated with poverty"—the rate of TB spread is higher (WHO, 2001). Many poor women and accompanying husbands who work long hours in manual labour or farming would lose a significant portion of their income while receiving treatment, specifically because TB generally affects people in their most economically productive years (S. Ahuja, personal interview, October 8, 2013). Those who are already in poverty may fall deeper into poverty due to the economic stresses of TB—perpetuating a cycle of poverty, sickness, and poor environmental work and living conditions. The occupations of women interviewed, and the proportion of the women who had to stop working for at least 10 days, is depicted in Figure 10.

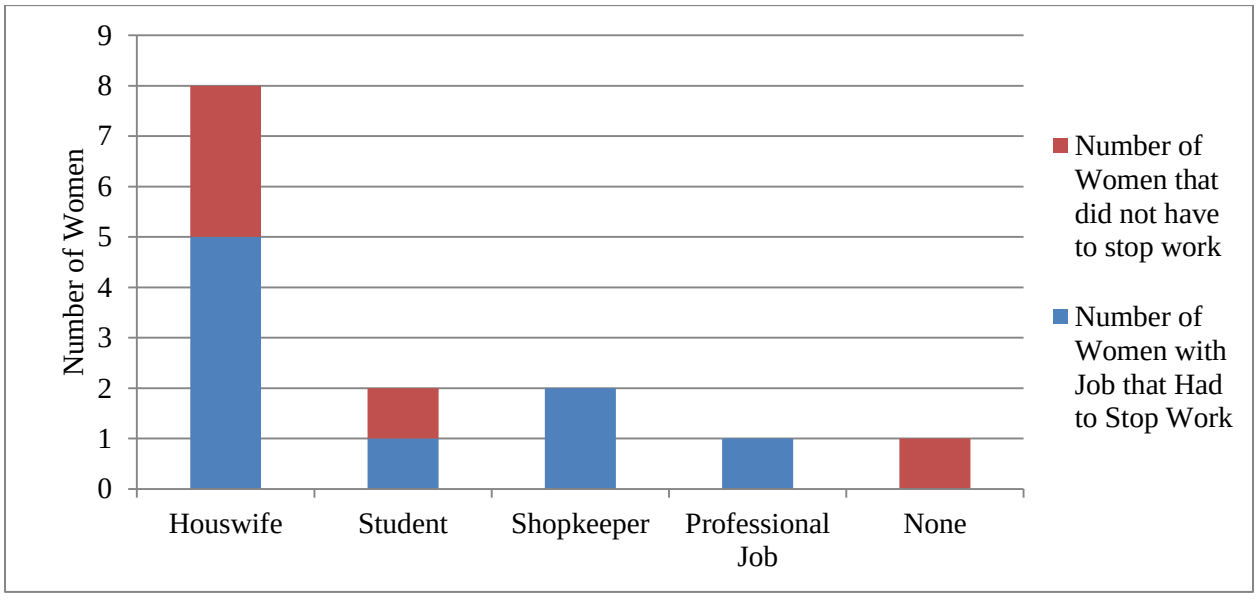

Figure 10. Occupation of Interviewees

Because government hospitals and DOTS centres may be farther than the closest health facility, costs of transportation is another economic barrier to treatment. One woman, Kavita,

when asked about what resources the government could provide to her to make treatment easier, quickly stated that if she could take the medicines at home it would be much better because then she would not need to pay the 20 rupees to get to the K. N. Katju Hospital for treatment (Kavita, personal interview, November 21, 2013). Although treatment itself is free, a one-way cost of 20 rupees would add up to almost 3000 rupees for the duration of treatment which is a very significant amount for a family below the poverty line, especially if the woman can no longer work or is too weak to cook or clean for her family.

Those who are poor and women are also less likely to have access to safe drinking water and sufficient nutrition—a critical economic barrier to effective TB treatment. Under-nutrition is "the most widely prevalent risk factor accounting for the highest population attributable risk (PAR) for TB in India" and those who were previously under-nourished have a higher risk of death and relapse in other settings (Bhargava et al. 2013). Women who face many other factors as previously described are also more likely to have a nutritional deficit. As previously discussed (Figure 8), a larger proportion of woman's treatment outcomes were classified as failure, even if they did complete treatment. This is likely due to under-nutrition.

Currently, "neither WHO guidelines for treatment of tuberculosis, nor International Standards of Tuberculosis Care" discuss nutritional support, though the Universal Declaration of Human Rights states that everyone has a right to food and security in event of sickness (Bhargava et al. 2013; WHO 2001). TB programs should address nutrition as an integral part of a successful treatment in parallel with food as a basic human right and should also address preventative measures to reduce undernourished-related immuno-compromised cases of TB. Dr. Jitendra Chaturvedi, the chief executive at DEHAT, a Bahraich-based NGO focused on empowering, mobilizing, and educating marginalized populations, suggested that any effective

NGO or governmental program addressing the challenges of TB should provide a diet component because he has seen that many impoverished patients will prioritize their resources and energy towards their immediate and short-term needs, like their next meal or day of work, over their less obvious long-term needs like adhering to treatment. Providing a diet component would allow patients to focus on their treatment and help ensure treatment's efficacy without having to worry about food security (J. Chaturvedi, personal interview, October 19, 2013). Seema explained that the Bhopal TB Hospital provides nutritious meals for all in-patients free of cost but fears that once discharged and managing their TB alone "there will be nobody there to tell them to take food. They will once again become negligent and unable to adequately care for themselves and all of the treatment and hospitalization will be useless" (Seema, personal interview, November 13, 2013). A sustainable and feasible way to address the underlying economic barriers to adequate TB treatment for women, like the difficulty with obtaining adequate nutrition, must be further explored.

4.3 Accessibility

As previously discussed, accessing adequate health facilities which provide proper diagnoses and the DOTS programme may require farther travel than the closest private clinic. The average distance travelled for treatment of those who reported a numerical value is 5.3 kilometers; however, two women stated that they live close-by and four from the TB Hospital currently live where they receive treatment. Because Bhopal is a large urban city, accessing one of the DOTS centres is not as large of a barrier as it is in rural areas; however, five kilometers is a long distance. Of the women who travel for treatment, three travel by motorbike, three travel by car, one travels by city bus, and two walk. In travelling by city bus, due to large crowds and

small unventilated spaces, rates of infection transmission are increased; however, the bus is the only way a woman unable to drive can hide her diagnosis which is due to the underlying socio-cultural barrier already addressed: stigma (Seema, personal interview, November 13, 2013). Because of difficulty travelling, three of the women (30 percent) suggested that they would rather take or receive their treatment at home (Pooja, Shruti, Kavita, personal interviews).

In addition to distance and time to treatment, it is more difficult for women because many are not independent and cannot seek treatment without access to their husband or father's vehicle. When asked if women usually come to the DTC for treatment or to present symptoms alone, Dr. Manoj Verma said that he has almost never seen women come by themselves and that they mostly come with their husbands but if they are scared to come with their husband, sometimes female friends or sisters come (M. Verma, personal interview, November 11, 2013). Of the patients who travel for treatment four came with their husband, two with their father, one with their grandmother, and two alone.

Despite some women preferring to receive treatment at home, accessibility and distance to treatment was not a large barrier for the urban Bhopali women interviewed as all of the women who travelled for treatment had never missed a dose. The largest accessibility barriers uncovered were due to other underlying barriers such as stigma, cultural roles of women, and misinformation.

4.4 Knowledge

The most prevalent and alarming barriers detected were those related to a lack knowledge or awareness about TB. Knowledge-based barriers are prevalent throughout the whole process of treatment and diagnosis on both the side of patient and side of the medical provider especially at

step 2, help-seeking behaviours; step 4, diagnosis; step 5, provider treatment practice; and step 6, patient treatment behaviour (Figure 1). The biggest challenge in case detection, diagnosis, adherence to treatment, and successful outcomes for Bhopali women and the RNTCP in Bhopal is a lack of awareness (M. Verma, personal interview, November 11, 2013).

Help-seeking Behaviours and Diagnosis Rates

Because of the social stigma surrounding TB, critical details about the disease are almost never discussed in social, educational, or familial settings. Although TB is the third largest killer of women, only two of the women interviewed had ever even heard of TB before their diagnosis (Pooja, Shruti, personal interviews). Of the two that had heard of TB prior to diagnosis, neither had known what really caused the disease, what treatment consisted of, or the severity of the disease. Dr. Manoj Verma (November 11, 2013) expressed the challenges of awareness as a large barrier for women:

> Awareness is a problem because they have to come to us at the time of 2 weeks [of being symptomatic], but many times they come after 1 month, 2 months, 4 months, 1 year, 2 years, 3 years. They go to quacks, talk to unqualified practitioners, take home remedies, then a few medicines from a chemist's stop. Very few populations know [about TB]. There is a lack of awareness in the mass. Most who are educated are aware, but not everybody is [educated]. And especially in India, education status is less in women so they are much less aware. Increasing awareness and education for women is the next step.

In addition to a general lack of awareness about TB, there is a lot of misinformation about TB, what causes it, and its ability to be cured. Many patients view TB as a very dreadful and hopeless disease which cannot be cured. Furthermore, many of them are frustrated from failings of the private sector and give up on seeking or taking treatment which can lead to

acquired drug resistance among other problems (Seema, personal interview, November 13, 2013). Much of the stigma associated with TB is due to this lack of knowledge about contagiousness and curability, but also due to other misinformation, such as disease-associated infertility or a genetic-basis for disease that they would pass onto offspring—both of which would make them less desirable candidates for marriage and push them into isolation. Additionally, both women who had been aware of TB before diagnosed expressed extreme shock that they could be affected by TB. Pooja expressed this when she was diagnosed she was very surprised because she "was not mentally prepared" that anybody like her—a young, educated, and working woman—could ever suffer from TB (Pooja, personal interview, November 18, 2013). She did not think that her cough could be a symptom of TB and did not go for diagnostics until her uncle, a doctor, told her that it was possible for her to have TB.

Because TB is viewed as a private, secretive, and stigmatized subject, even once a patient is cured they almost never tell anybody in their community about their successful treatment. This hinders the spread of correct information about TB treatment and may be a reason that the stigma and negative perception about TB still persists. Of the women interviewed, five said that even after they were diagnosed, their community and neighbours still do not know about TB and three said that they do not know what their community knows because they never talk about it. Dr. Chaturvedi stated that the focus of a successful TB eradication program cannot solely focus on service delivery and that they must focus on awareness and de-stigmatization. To do this, he suggested a program for cured patients to "spread the message" and serve as leaders or motivators for the community to become aware about TB (J. Chaturvedi, personal interview, October 19, 2013).

Not only is there a lack of knowledge about TB as a disease, but there is still a lack of awareness of the availability of free high-quality diagnostic and treatment facilities locally under the government scheme—even after more than a decade of RNTCP implementation (Ramachandran, Muniyandi, Gopi & Wares, 2010). The pre-diagnosis obstructive help-seeking behaviours are characterized in Figure 11. One woman, Fariha, did not remember because she has been on-and-off TB treatment for 11 years since she was diagnosed.

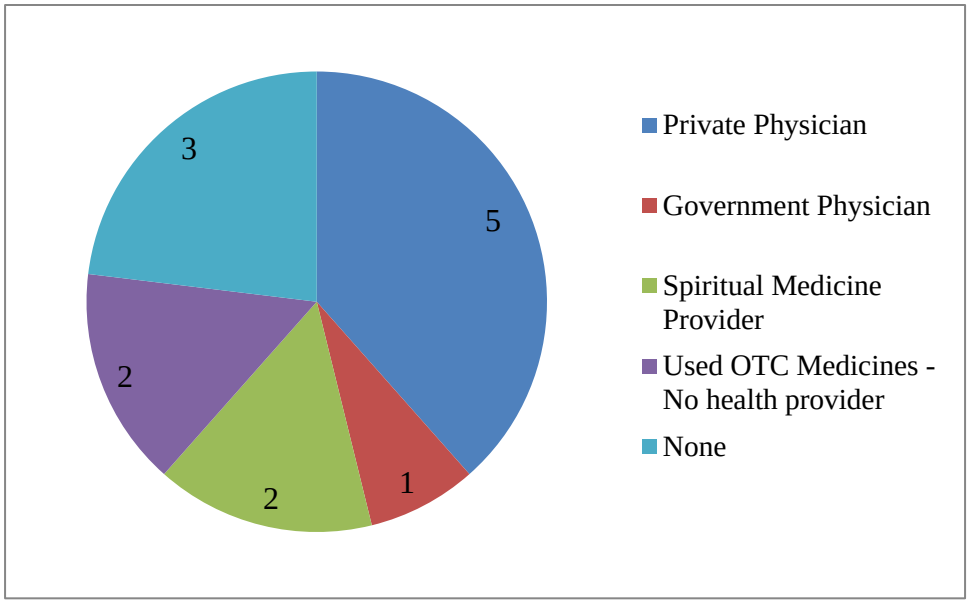

Figure 11. Unsuccessful Pre-diagnosis Help-seeking Behaviours

More than half of the patients (62 percent) sought help and visited at least one practitioner who did not diagnose their active TB. This suggests a lack of education on the part of the health providers to refer symptomatic patients for testing at the DMC. Not only was this negligence found in the spiritual and private sectors, but one patient, Safa, failed to receive a referral from a Bhopal government Primary Health Centre (PHC). Previous research has suggested a possible physician-bias to refer more men for diagnostic testing because of the view of TB as a man's disease (ACTION, 2010). However, the health workers interviewed suggested

that based on the symptoms, they equally refer men and women of all ages and gender plays no role in reading sputum sample slides (Seema, R. Kumar, S. Patel).

The RNCTP suggests that all patients who are symptomatic for three weeks be given a sputum smear examination; though, because of these knowledge-related barriers to help-seeking many women spend much longer feeling symptomatic before they receive a diagnosis. Of the 11 women who could remember how long they were symptomatic before diagnosis, the average time was 4.5 months and median was two months. Figure 12 shows the amount of time women felt symptomatic before diagnosis overlaid with their average age upon diagnosis.

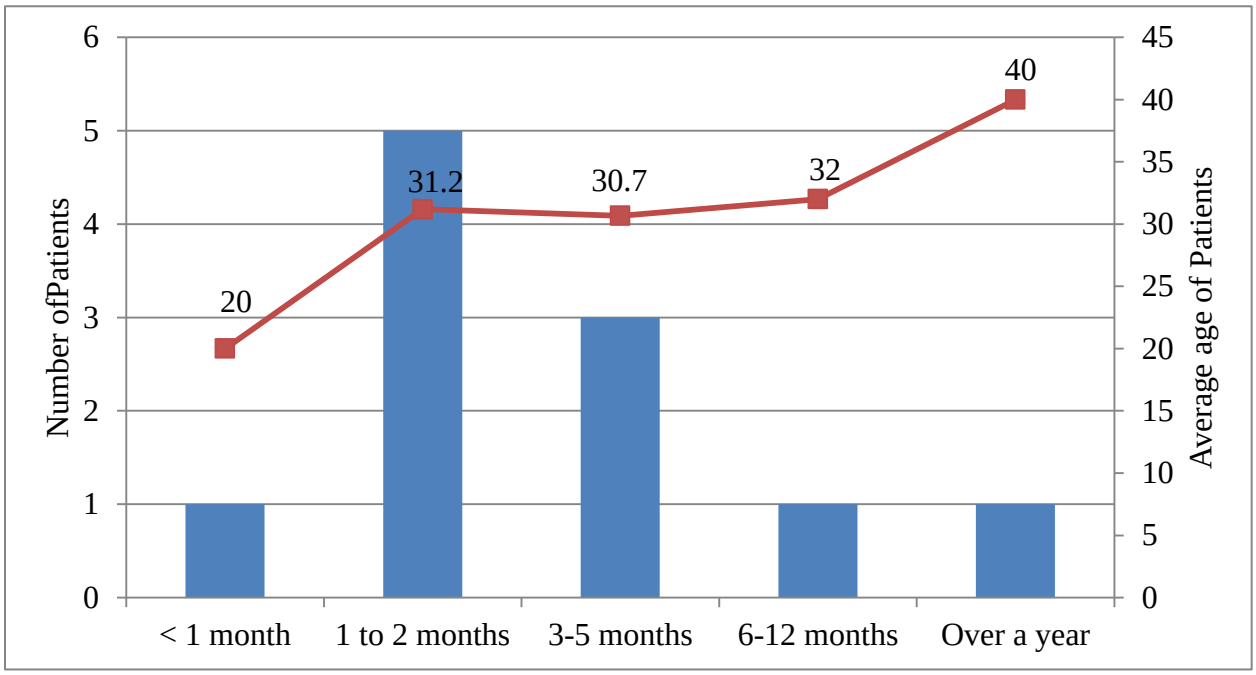

Figure 12. Time Symptomatic Before TB Diagnosis Plotted with Average Age of Patients

Figure 12 depicts an interesting correlation between age of patient and the amount of time the patient spent symptomatic before diagnosis: as patients get older, the time that it takes for diagnosis—including the time spent ignoring symptoms, self-treating symptoms, looking for care providers, and receiving treatment from unqualified practitioners—is longer. This suggests that

there are greater barriers to diagnosis for elderly women with TB and may explain the trends found from the Bhopal RNTCP data depicted in Figure 4 (section 3.1) and Figure 7 (section 3.2). The trends previously examined showed that a greater proportion of those who present with symptoms, those who are tested for TB, and those who are diagnosed with TB are younger women. While this could be explained biologically—women may be more susceptible to TB at younger ages due to childbearing or other factors—this skewed proportion of younger to older women could also be a result of a lower proportion of cases detected in elderly women due to the additional barriers that elderly women face, as suggested by the data presented in Figure 12.

The barriers to diagnosis that older women face are not clear; however, it was previously discussed that younger women are more likely to face socio-cultural barriers of stigmatization, which suggests that older women face a different set of barriers to diagnosis. One such barrier which may more disproportionately affect elderly women is a lack of awareness. Both women who had heard of TB before diagnosis were under 25 years and one expressed that she had heard of TB through schooling (Shruti, personal interview, November 20, 2013). Elderly women may have less exposure to media or information about TB or RNTCP and may also have less educational background (though this specifically was not investigated).

Provider Treatment Practice and Patient Treatment Behaviour

While there are many knowledge-related barriers to accessing diagnosis and treatment, there are also obstacles to effective treatment. Although when diagnosed, patients are supposed to be told about TB, its treatment regimen, the importance of adhering to treatment, measures to prevent spread of TB, and importance of nutrition to treatment, many patients interviewed were not aware of or ever told these things. Multiple patients still were not aware of what TB is or how they got it. Almost all patients at diagnosis were told about the duration and schedule of

treatment, symptoms to be aware of for family members, and that the drugs are important; however, only one patient was told of the importance of nutrition and only three about preventative measures. One patient, Safa (November 12, 2013), described that she was never told about TB because the doctor only told her mother. Another patient was aware that the "cough is cured by taking medicines" but not of the underlying problem (Divya, personal interview, November 18, 2013). This misguided knowledge about TB could be detrimental to treatment success because after a few weeks or months of treatment, the exterior symptoms are cured, though the active infection still exists. If a patient believes that only the cough needs to be cured, she may stop treatment, which could lead to drug resistance. If a patient believes that treatment is no longer necessary, they will almost always stop because of the rigor of treatment and its side effects (Seema, personal interview, November 13, 2013). Debilitating side effects were expressed as the most difficult part about treatment for all women. One woman, Fariha (November 13, 2013), who has been starting and stopping treatment for 11 years cited the side effects as her reason for stopping. It is, therefore, critical to accurately express the purpose of the drugs and the importance of adherence to treatment.

5 CONCLUSION

The D.O.T.S. strategy is standard and effective; however, it assumes that women can recognize TB symptoms, feel confident to seek treatment, and have access to the treatment multiple times per week (Ravi, 2012). The purpose of this study was to investigate these barriers that the women of Bhopal face in receiving adequate TB care and to examine the resulting inequity of care. Through informational and statistical analysis of available RNCTP data, this

study shows that there is gender inequity in both diagnostic rates and treatment outcome for women in Bhopal. Through the synthesis of quantitative data and field work, many of the barriers that cause these gender differentials in TB care have been investigated and characterized. Barriers such as lack of knowledge, cultural perception of TB, and accessibility cause many women to ignore their symptoms or see other unqualified providers who cannot diagnose their TB, which leads to greater rates of transmission, worse treatment outcomes, frustration, depression, and financial drain. Subsequently, these can affect food security, efficacy of treatment, compliance, and likelihood of acquiring drug resistance.

While the barriers investigated are all intertwined and greatly affect each other, the most prominent obstacles that women face are likely different given their ages. Younger women more greatly face socio-cultural barriers and stigma, while older women are less likely to have any awareness about the disease at all. These distinctions and nuances are important to further investigate and to consider when developing a gender-sensitive TB control program.

TB has been depicted as a horrendous and incurable disease that only affects elderly men. Due to this picture and the misinformation surrounding TB, stigma has persisted for years. The lack of community awareness and failure to publicize the available, free, and effective DOTS treatment have prevented many women from accessing diagnosis and treatment—leaving many unreached and silently killing India's women.

Transitioning to community empowerment, de-stigmatization, and human-rights based approaches to TB control is a necessary step to supplement the service-based approach of DOTS. This transition is integral to developing an equitable approach to controlling TB, as stigma has been shown to have a more prominent effect on "women, poor, and less educated" community and this stigma may widen the health disparity in these groups where a health disparity may

already exist (Courtwright & Turner, 2010). Although DOTS has been effective in reaching numerical targets, reaching women who have reduced ability to receive adequate TB diagnoses is critical to ultimately achieve TB eradication.

5.1 Limitations

While information gathered from all interviewees sheds invaluable light onto the barriers that they faced in their diagnosis and treatment, the women that are most burdened by these barriers are those who could not be interviewed and still go undiagnosed with TB. Additionally, women who have stopped treatment and have not returned were not able to be interviewed. It is impossible to truly know the numerical extent of the population of women who go unreached and it is therefore impossible to know the barriers that they face.

Another limitation was the language barrier between research subjects and researcher. A health provider who worked at the OPD or hospital served as a translator; however, the degrees of translation accuracy and completeness varied. Because all translators worked for the RNTCP, translator bias may have played a role in shaping the answers. All interviews were recorded and any suspected translation discrepancies were re-translated for accuracy checking. Because of the translator's presence and because some women were accompanied by family members while being interviewed, the answers may have been influenced. Additionally, because the researcher, who many times was perceived as a foreign outsider, was present answers may have been biased.

Finally, because the sample size for the field study component of the study was small, statistical significance could not be obtained and accordingly all conclusions should be viewed as qualified.

5.2 Suggestions for Future Research

It is important to continue research in this area to further validate the results presented in this study and to aggregate additional information so that appropriate gender-sensitive programs can be best implemented to address the specific obstacles women face. One major trend of interest found in this study was the difference in barriers that women of different ages face. Future research should further explore these correlations and additionally explore the differences in barriers that other groups face. For example, what are the differences in barriers that women of a higher socio-economic group face? Or what are the differences in barriers that women of different religions face? Additionally, this study aimed to uncover the barriers for women; however, no men were interviewed as controls. Future studies could explore the barriers that most hinder the diagnosis or treatment of men and compare them to the barriers found here. Finally, this study focused on one stigmatized disease; however, these methods could be used to evaluate the barriers to diagnosis and treatment of other stigmatized diseases prevalent in India and across the world such as HIV/AIDS.

The completion of such research projects would provide extensive knowledge regarding the intricacies of the barriers that women face when confronting TB or other infectious diseases. This body of knowledge could be used to develop policies, programs and educational campaigns to start an informative dialogue about TB and to try out different kinds of interventions. Demystify the disease and making information, counselling, and treatment available to communities like Bhopali women would help to bring TB out of the silence and would allow India to move forward with the goal of eradicating TB.

6 APPENDICES

6.1 APPENDIX 1: Patient Profiles

District TB Centre, DOTS Centre – November 12th, 2013

Gayatri: 40 years, seamstress, sputum-positive pulmonary TB, diagnosed 2 months ago

Safa: 20 years, works at a parlour, sputum-positive pulmonary TB, diagnosed 5 months ago

Bhopal TB Hospital, Idgah Hills – November 13th, 2013

Fariha: 35 years, housewife/not working, pulmonary TB, diagnosed 11 years ago, does not take medicines regularly

Lakshmi: about 70 years, not working, pulmonary TB, diagnosed 6 months ago

Aditi: 32 years, housewife, pulmonary TB relapse case, diagnosed 6 months ago

Disha: 22 years, not working, MDR-TB, diagnosed 1 year ago

AIIMS Bhopal OPD, DOTS Centre – November 18th and 20th, 2013

Pooja:24 years, software developer, sputum-positive pulmonary TB, diagnosed 2 months ago

Chandni: 18 years, student, sputum-positive pulmonary TB, diagnosed 1 day ago, starts treatment after interview

Komal: 50 years, housewife, sputum-positive pulmonary TB, diagnosed 2 weeks ago

Shruti: 23 years, housewife, critical case: was diagnosed extrapulmonary TB but after completing intensive phase treatment was diagnosed sputum-positive pulmonary TB, diagnosed 3 months ago

Madhu: 26 years, housewife, extrapulmonary TB of lymph node, diagnosed 1 month ago

K. N. Katju Hospital, DOTS Centre – November 21st, 2013

Kavita: 65 years, housewife, sputum-positive pulmonary TB, diagnosed 2 months ago, maternal grandmother of patient 13

Preeya: 20 years, student, sputum-positive pulmonary TB, diagnosed 9 months ago, completed treatment, granddaughter of patient 12

6.2 APPENDIX 2: Interview Questions

DTO Interview Questionnaire:

1. What is your role as District TB Officer?
2. Approximately how many TB units, microscopy centres, and DOTS centres are in Bhopal?
3. Where does Bhopal receive its supply of TB drugs from (a nearby State Drug Store?)? Have there been problems in drug logistics or ever a shortage of drugs? Or diagnostic instruments?
4. What is the strength of Human Resource in Bhopal? Has there been a shortage of staff or do you perceive more staff is necessary?
5. What challenges does Bhopal specifically face with regards to TB?
6. What do you perceive to be the largest barriers or challenges for patients with TB to receive adequate TB treatment and diagnosis? And are the challenges/barriers that women face different in any way?
7. Do many people know about TB?
8. What do you think would be the best way about creating awareness would be to motivate people to come?
9. Do you believe a stigma still exists against women with TB (in Bhopal)?
10. What are the next steps to increasing TB treatment compliance and increasing diagnosis for women with TB in Bhopal?
11. Do the DOTS providers receive training? What kind?
12. How far do people come to visit this centre for treatment? Do women usually come alone or along with somebody?
13. When receiving treatment can patients still work and carry on normal lives?
14. Do patients have to pay for treatment? If so, how much? Are there other expenses that TB patients incur?

Health Care Provider Questionnaire (Questions adapted for specific professionals):

1. What is your name? What is your role/job?
2. How many people visit this centre for treatment? How many people are diagnosed here?
3. Where are patients referred from? Where is the closest DMC? How far do people come to visit this centre for treatment?
4. What criteria do you use to refer patients to the DMC? Are the criteria different for men and women?
5. When diagnosed, what do you tell the patient? Or what is the patient told? Is there counselling available?
6. Do patients have to pay for treatment? If so, how much? Are there other expenses that TB patients incur?

7. Do women patients usually come alone or along with somebody to receive treatment?
8. Do you believe a stigma still exists against women with TB (in Bhopal)?
9. When receiving treatment can patients still work and carry on normal lives?
10. What do you perceive to be the largest barriers or challenges for patients with TB to receive adequate TB treatment and diagnosis? And are the challenges/barriers that women face different in any way?
11. Do many people know about TB?
12. What do you think would be the best way about creating awareness would be to motivate people to come?
13. What are the next steps to increasing TB treatment compliance and increasing diagnosis for women with TB in Bhopal?

Patient Questionnaire – English Translation:

1. What is your name? Age? What is your work?
2. When were you diagnosed with TB? How long did you feel sick before you were diagnosed?
3. Did you see any other doctors or take any other medicines before you were diagnosed?
4. What did you know or think about TB before diagnosed?
5. Why did you decide to seek treatment?What was the hardest part about seeking treatment?
6. When you were diagnosed what did the doctor tell you about TB and/or the drugs?
7. How often do you come for treatment? How far do you travel? How do you come? Who do you come with?
8. Have you ever had to miss a treatment? Why?
9. Is there any change in your life after diagnosis?
10. What is the hardest part about coming for treatment and having TB?
11. Did you have to stop working?
12. Who knows about your TB diagnosis? Did you hide it from anybody? Why?
13. Have you ever felt stigmatized or ashamed to have TB?
14. What does your community know or think about TB?
15. What tools could the government provide that would help you most?

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