The Sound of Silence: An Ethnography of Poor Women With Tuberculosis in Bangalore, India

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August 2005
Abstract

Though there is a long history of tuberculosis, there is not a long history of gender-focused, anthropological studies in Bangalore, India on tuberculosis. Most health social sciences in the third world have studied tuberculosis (TB) in isolation from gender, focused on the poor, and have an absence of ethnographic content. As a result, little is known on the lay woman’s perspective of TB in Bangalore, India and how this influences her health seeking behavior, concept of illness, and the role of stigma. This explorative ethnography was designed to elicit what women in Bangalore, India do when faced with TB, and hopes to bridge the gap in research.

Women in this study are members of the lower caste, and economically fall at the poverty line or below. Data was collected through semi-structured open-ended interviews and participant observation with women and professionals in the filed. The meanings and experiences of TB were found to be linked to stigma, gender, power, agency, and structural violence. Prompt medical care to women infected with TB may be compromised by delayed medical help seeking and diagnosis from competent providers (Morankar and Weiss 2003: 149). When women get infected, they are often sent back to their parental home for treatment, or they may be deserted. Though government sponsored medical care is available to the public, which includes free medical treatment for TB and educational campaigns, the Directorate General of Health Services, Ministry of Health and Family Welfare India state “More adults die from TB than from any other infectious disease in India —1 every minute, more than 1,000 every day (www.tbcindia.org/Key.asp)”. With proper treatment, known as DOTS, an acronym for Directly Observed Treatment, Short Course, Tuberculosis is completely curable (www.tbcindia.org/Key.asp) according to the medical perspective. I will explore the paradox of available treatment, yet an unavailable cure.
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Dedicated to The Women of Sri Ramapuram, Working Woman’s Forum (India)

Family & Majid

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Acknowledgements:

I hope that this thesis inspires those who read it and springs into action some changes. I would now like to voice my sincere thank you and gratitude. I am most obliged for the kind help, support, and assistance of everyone that has helped me, and very fortunate to have received it. With out the help of everyone involved, my project would not have been possible. I am grateful to all parties that enabled me to carry out this vision. I would like to extend my sincere gratitude to Dr. Vijayalakshmi, who granted permission for this study. I am deeply thankful and indebted to the Working Woman’s Forum, who so kindly assisted me in all steps involved in this project making it possible to carry out the project, and so generously provided my lodging in India. A special thank you to Dr. Schenk-Sandbergen, who introduced me to the Working Woman’s Forum (India) and encouraged me to persevere. I am most grateful to the doctors, Mohan, and S. Saravanah at SriRamamupa Hospital for being so accommodating and very helpful. I also am so grateful to have worked with Roseline, who provided excellent translation and allowed me the freedom to interact with the women.

Dr. Jaya Arunachalam, Sudah & Staff, Working Woman’s Forum Chennai (Madras)
Dr. Indrimma, and all the wonderful Staff, and cook, Working Woman’s Forum Bangalore
Dr. M. Viayalakshmi, Dr. Ramakumari, Bangalore Mahanagara Palike
Dr. Shamlia, Dr. N. Amaresh, Dr. A. Gaddi, SriRamapura Referral Maternity Hospital
Mohan, and S. Saravanah, DOTS Center, SriRamapura Referral Maternity Hospital
Roseline, Translator
Dr. Loes Schenk-Sandbergen,
Dr. Diana Gibson, University of Amsterdam;
Chapter I

Introduction

Tuberculosis is a contagious disease transmitted by *M. Tuberculosis* (Pulmonary tuberculosis) via inhalation of small airborne droplets (Nichter 1994: 650). These bacilli harbor in the lungs if not eliminated by the immune system (Nichter 1994: 650).

Tuberculosis (Mycobacterium tuberculosis) has been present in the human population since antiquity. This infectious disease has been found in Egyptian mummies from 2400 BCE and noted by Hippocrates in 460 BCE. Hippocrates identified ‘Phthisis’ (what we know as tuberculosis) as the most widespread disease of the times, and noted that it was ‘almost always’ fatal (www.umdnj.edu/~ntbcweb/history.htm). In India, tuberculosis has been mentioned in the Ayurvedic Samhitas (Gothi 1982: 134). There is a long history of tuberculosis, however, most health social sciences in the third world have studied tuberculosis (TB) in isolation from gender, focused on the poor, and have an absence of anthropological content. As a result, little is known on the lay-woman’s perspective of TB is and how this influences her health seeking behavior and her concept of illness. Programs are available to the public, free medical treatment for TB and educational campaigns. The Directorate General of Health Services, Ministry of Health and Family Welfare India state “More adults die from TB than from any other infectious disease in India — 1 every minute, more than 1,000 every day (www.tbcindia.org/Key.asp)”. With all that is available, we have to ask what is happening here? Tuberculosis is completely curable from a medical perspective, but as we look further, we see that a social cure is far from available. I will explore this paradox in the course of this thesis.
1.1 Project Aims

I completed a four-week ethnographic study of women with TB and their health seeking behavior. I focused on in-depth semi-structured interviews, participant observation, and follow up interviews. Research took place in Bangalore, Karnataka in South India. I based my study in Sriramapura Referral Maternity Hospital, which has a D.O.T.S (Direct Observation Treatment, Short-course) Dispensary inside. An opportunistic sample of 12 lower-class, lower caste women aged 18-60 participated in this study. These women were interviewed about their experience and perceptions about having TB. In addition, the same women completed a body-mapping interview to gain insight on their perceptions of health, illness, and disease. The body-mapping interview was a questionnaire focused on questions surrounding women’s concept of health, illness, and disease. My interpreter, Roseline, was from the surrounding area, and a Christian, which was beneficial in working with Hindu and Muslim lower caste and class women. The religion factor buffered the caste and class dynamic between informants and the translator which could have created a social barrier associated with the Hindu caste system.

In this project, I had three aims to document women’s experience with having Tuberculosis in Bangalore, India. The first was to document their experience with TB, second, to gain insight into how they view their body in health, illness, and disease, and third to interview the medical staff working at the DOTS dispensary. My first aim was to form a picture of the women’s experience with tuberculosis and the DOTS program by interviewing the women and spending time with them. Health seeking behavior was a critical component of my study, as with out a concept of what tuberculosis means to the women, my main aim of documenting the women’s experience of having tuberculosis and seeking care would have proved inadequate. Further views regarding stigma emerged and proved to be a very important component of this study which affected women’s day-to-day lives and is linked to agency and structural violence.

My second aim was to gain insight into how they view their body in health, illness, and disease. This aim helped to develop a clear picture of a women’s perception of body and
related to their experience with tuberculosis through their concept of body. Without this aim, I would have lacked insight into the women’s concept of the body health illness and disease and could not have represented their experience of tuberculosis in context. I could have researched this apart from TB, but the body mapping was taken into context and framed around TB. If I did not include this aspect, due to lacking anthropological data, I would have presented an unclear picture.

My third aim was to interview the medical staff working in the DOTS dispensary. This aim provided an additional view of tuberculosis. It helped to form a total picture of the health care setting and environment. By documenting health care provider’s viewpoints, experience, and perceptions, provided an important component to describe the health care setting and the women participating in it. By documenting the experience of health care providers, it helped to provide a complete ethnographic description of tuberculosis. By including the medical staff in this study helped to compare their viewpoint to the women and gain insight into their perspective.

1.1.a. Research Questions

My main research questions involving women were:

1. What happens if a woman has tuberculosis?
2. Who do you tell if you have tuberculosis?
3. What are the woman’s perceptions of the body in health, illness, and disease?

For medical staff working in the DOTS dispensary, my main questions were

1. How do women describe tuberculosis symptoms?
2. What do you think of DOTS?

These key questions I asked referred to descriptive and/or task/activity questions, experience questions, opinion and meaning questions, feeling questions, knowledge questions, and hypothetical questions. Through these specific types of research questions, I hoped this method would provide a clear, well-rounded picture of women with TB, the health care providers that serve them, and their individual experiences with in this context.
On a theoretical level, these questions address the women’s position in society, power, agency, and social hierarchy in India. My aims and research questions provided the framework for my project.

1.1b. Explanation of Methods Used

I used multiple field methods including: semi-structured open-ended interviews, participant observation, photography, and body mapping. At the hospital, there were 70 tuberculosis patients’ 50 men, and 20 women. The women live in the surrounding area and visited the hospital regularly for DOTS treatment. The women were in various stages of recovery from diagnosis, to three months of treatment. I interviewed 12 women and 3 medical staff. The Working Woman’s Forum, a grassroots NGO that focuses on micro-lending in Bangalore set up the initial contact with the hospital. Through this contact, I gained entry into the hospital. I did not have any pre-existing contacts of women with tuberculosis in Bangalore. My sample was opportunistic, as the women I interviewed participated in DOTS and were inclined to be at the hospital the days DOTS operates Monday, Wednesday, and Friday. Additionally, the laboratory worker would sometimes refer women to me to be interviewed.

My observation methods consisted of structured observation and participant observation. All observation took place within the hospital compound. The DOTS official hours of operation were between 9:30 am and 4:30 pm on Monday, Wednesday, and Friday. I tried structured observation for one hour with detailed notes. The structured observation was very difficult to complete and lasted fifteen minutes. With the sensitive nature of my topic, I did not wish to cause anxiety or single out people. I unobtrusively sat on a bench in the hallway, which is the waiting area where all patients wait. I attracted a crowd of about 10 women around me that observed me while my purpose was to observe them. In addition, during part of the structured observation time, I was asked repeatedly what I was doing and succeeded in telling people I was observing, and not to mind me. As the first foreigner to visit the hospital, the structured observation did not allow me to ‘blend in’ and made me draw unnecessary attention to myself. I concluded that the structured observation approach was not conducive to the environment I was in. I found it difficult to take notes.
among the patients. Though the medical staff was aware of my project, I raised suspicion with patients surrounding my presence in the hospital. The patients thought I was a missionary worker or thought I wanted something from them. Once I quelled their suspicions by openly answering questions, I was commonly mistaken for a doctor, as one maternity patient said “because you are writing on paper”, and finally, patients were taken aback to see a foreigner in the hospital, (there were not any foreigners in the hospital before me) and became confused as to why I was there in the first place if I was not a doctor or a missionary worker.

Participant observation proved to be more effective than structured observation. By just sitting in a designated space like the Laboratory room, or vaccination room proved to be less invasive, and raised less suspicion. If I sat in a room and not the waiting area, it appeared as if I more official, rather than sitting in the waiting area with everyone else. Though I did not ‘blend in’ it was a better strategy to sit in defined spaces. I would observe events around me in the hospital waiting area at 5 to 20 minute intervals. These intervals occurred in between interviews, or after interviews. Though I would be stared at, and people would ask me what I was doing, I could answer their question and continue to observe. I would exit the location and write down my observations in the interview room at that time or document notes after I returned from the hospital. Roseline, the translator would accompany me and sit next to me, translating as necessary.

Pre-collected data includes information from my literature review. I obtained information from the Internet and the University of Amsterdam library. I used data from articles, medical journals, articles and books on Indian society, women, and structural violence. Whereas tuberculosis is a widely researched topic, an anthropological approach including women with tuberculosis in Bangalore, India has been under researched and I did not find much material on this exact topic. Relevant literature was collected to gain knowledge of the history, political policy, and research on my topic.

I completed a semi-structured open-ended interview and body mapping with all women. My key informants were Sonia and Yamini. These women are patients at the clinic. With
them, I completed semi-structured interviews and a follow-up interviews. These were in-depth and provided much insight into the woman’s world in Bangalore. Gaining insight into the woman’s world was an important component to understand their perspective. I had an exceptionally good rapport with these two participants. Though I did interviews with all women and established a good rapport, I felt that Sonia and Yamini were my key informants. I felt we had a good rapport, as they initiated interactions with me, and asked to talk with me, spoke to me in length and detail, and always sought me out on the days they came to the clinic. I felt I had a good rapport with all women, and especially Sonia and Yamini. Establishing a good rapport was important for the overall comfort of the women and learning from them. The women’s semi-structured open-ended interviews focused on collecting demographic information, nutrition information, and their view of tuberculosis. I aimed to discover their eating patterns who they talked to, which doctors they visit, economic standing, and stigma involved with the disease.

I completed a semi-structured open-ended interview with two medical staff, for whom I developed a different questionnaire from the women. I focused on their views of the patients, the tuberculosis program structure and to gather opinions and values the medical staff holds. I also had an unstructured interview with the hospital director who walked into her office and began talking about tuberculosis, it was more of a verbal free listing of her view of tuberculosis.

An additional method I used was body mapping. Body mapping interviews were only conducted with the women. I focused on the women’s view of the body in health, illness, and disease. I aimed for illness models, identification, and perceptions of the body to assist me with my interview data and the woman’s perspective of the body. The interview was completed the same day as the semi-structured open-ended interviews. Either a small break took place after the interview, or after the first interview completed, the women would wish to continue. The main objective was to understand how they identify illness.

Finally, I used photography. I used my digital camera to photograph inside and outside of the hospital. Due to the stigma associated with TB and protecting confidentiality, I did not
photograph any participants, unless requested to do so by the participant. Given the sensitive nature of my project, I have not included any photographs of participants. Otherwise, I was allowed to photograph the whole hospital premises and surrounding area. This method was useful to identify the location but not very practical for anything else. I used this data as a kind of illustration. Photos included in this work have been consented for use by the people pictured.

1.2. Ethnographic Setting, Physical Space, and Context

Bangalore is situated at an altitude of 920 meters above sea level, and is the principal administrative, cultural, commercial, and industrial centre of the state of Karnataka in southern India. The city, which is spread over an area of 2190 square kilometers, enjoys a ‘pleasant and equable climate throughout the year’ (www.bangaloreit.com/html/aboutbng/profile.htm). Bangalore is the capital of the state of Karnataka and Bangalore has been considered a hi-tech city since the early 1980’s. It is now home to more than 250 high-tech companies. Bangalore is called the 'Silicon Valley' of India (www.banglaoreit.com/html/aboutbng/profile.htm). According to the 2001 Census in India, conducted every decade, there are 1,027,015,247 billion people in India. Karnataka has a population of 52,733,958. There are 17,919,858 people living in urban areas. However, the data used in this literature on India was disproportionately based on the 1991 census. In 1991, there were 44,977,201 urban people. This number has increased dramatically over the last four years, and Bangalore attracts many people flocking to the city to ‘make it big’. The traffic has also increased very dramatically bringing this thriving city to a gridlock throughout most of the day.

Access to the hospital became an unexpected barrier1. In addition to doing field work in during monsoon season, Auto-rickshaw drivers were not interested to venture into SriRamapuram. Roseline the translator and I attempted to circumvent this barrier by taking the bus. The bus took nearly one and a half hours one way, which resulted in missing busy morning hours at the clinic. I was unwilling to miss the mornings, so we resorted to taking

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1 See Appendix, ii, Image 1
the bus on the way back to the Working Woman’s Forum. There was not any lodging closer than where I stayed.

Figure 1: Sriramapura Referral Maternity Hospital (SRMH): There are no signs for a DOTS Center

The Sriramapura Referral Maternity Hospital (SRMH) is physically located in the gritty precinct of Sriramapuram in Bangalore, Karnataka. Sri Ramapuram is located about forty-five minutes by auto-rickshaw from the city center of Bangalore. The hospital serves a very local population. People arrive at the hospital by walking, at a maximum of 30 minutes away. Only two informants came via bus, and it took one informant thirty minutes each way and the second informant it took about three and a half hours total. One kilometer, according to the hospital director, is far. “Beyond one kilometer, people will not walk to the hospital or come.” This government hospital serves the poverty line and below according to the participants, the doctors, director, and two TB staff. The hospital has a
The ‘hi-tech’ operation room, a maternity ward, and one small room allocated as the DOTS center. This room is called the Laboratory and is the diagnostic center for TB. This room has a microscope, which is used for an array of things, including sputum examination. This room also has an early model centrifugal machine utilized for blood and urine. The laboratory technician is responsible for DOTS, HIV tests, and blood tests for maternity patients.

The DOTS dispensary is located inside the Maternity Hospital. There is no sign in the front of the hospital, indicating there is a DOTS center here. This dispensary serves 1 lakh population and has two staff members and a visiting supervisor. The TB patients are not to be confused with the maternity patients. The DOTS program is not affiliated with Maternity Hospital or Urban Family Welfare Center. DOTS is an entirely separate program under the umbrella of the World Health Organization, that just happens to be located in a Maternity Hospital. DOTS takes place every Monday, Wednesday, Friday and every second Saturday. The majority of the TB patients arrive at around 9am –11am. By 11am, it is down to the occasional patient will come up until 1:30 pm. The staff leave for lunch depending on the volume of patients, between the hours of 12:30 and 2 pm and return by 2:30.

The Sriramapura Referral Maternity Hospital (SRMH) is one of six referral hospitals in this municipal area and serves four to five lakhs population. SRMH is also one of five Urban Family Welfare Centers (UFWC) in Bangalore. There are 34 beds at this hospital, averaging at least 25-30 live births monthly, maximum 70 to 80 live births. The doctors generally see 30-40 maternity patients a day. Nearly 25-40 vasectomies preformed monthly and other surgery. There is one supervisor and five doctors, of which, there are three gynecologists, one pediatrician, one anesthetist and an MBBS, undergraduate. There are three staff nurses and Auxiliary Nurse Midwives (ANM’s). The hospital’s official hours are the same as DOTS 9am –4pm, with five doctors on duty daily, four in the

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2 See Appendix, i ,Note 1

3 1 lakh= 100,000
daytime, and one overnight from 8pm –8am. This hospital is a noisy and crowded place in the morning time, although it seems more crowded than it actually is because the waiting area is a narrow hallway filled with maternity patients, TB patients, and a blasting television. TB patients, Maternity patients, new-born babies, and toddlers, share the long hallway known as the waiting area. Patients (maternity or TB) either sit on the wooden benches or mill about waiting their turn for the doctor or DOTS worker.

Figure 2: DOTS Dispensary, Sriramapura Referral Maternity Hospital

1.2.a. Srirampuram

This particular area of Bangalore is considered a ‘slum area’, which means most residents are living in abject poverty. All but three of twelve women are native Kannada speakers and have lived in Bangalore their whole lives. This area is home to a high number of Tamil speaking people, who have come from the neighboring state of Tamil Nadu. Tuberculosis is called Shiaroga in Kannada, and Putonoy in Tamil. These women refer to Tuberculosis
as TB. Women had various levels of education. Some left school at around the age of fourteen, while some had up to some college education. Women worked mostly in the informal labor sector and two women as a teacher and as a receptionist before marriage. Most women spoke Kannada, the language of Karnataka or Tamil, the language of Tamil Nadu, the neighboring state to Karnataka. The hospital was known to be in a “Tamil speaking area”, however, the participants spoke mostly Kannada. I later found out that since this area is labeled a “Tamil speaking area” it was supposed to indicate that this is a “slum area” due to the Tamil population. This is not an official indicator of a slum although, in this case, it is indeed a slum area. Rather, this is reflection of an attitude or stigma that “Tamil people live in slums” in Karnataka.

Of all the women participants, none interacted with each other in the hospital or knew each other. One participant was related to another, her daughter, who also had tuberculosis but received treatment at a private hospital and not a SRMH government hospital where she is currently under treatment. Once diagnosed with TB, by sputum examination, or x-ray, women are expected to come to the hospital for a period of six months.

1.2b. My Introduction to the Working Woman’s Forum and SRMH

My introduction to the DOTS program started in Amsterdam, Netherlands. For several months, I had been diligently contacting various tuberculosis programs in Bangalore, but to no avail. I had not secured a research location and I contacted Dr. Loes Schenk-Sandbergen, who provided me with contact information for the Working Woman’s Forum. I contacted them, and as chance would have it, Dr. Jaya Arunachalam, president and founder of the Working Woman’s Forum (WWF) in Chennai(Madras) India, was in Amsterdam for three days. I contacted her via telephone and arranged a time to meet. When we met, Dr. Schenk-Sandbergen and others were present as I conveyed my plan to Dr. Arunachalam. On 12 May 2005, five days before I left to India, I received confirmation they would assist me. This was a very lucky break, considering I wanted to work with the WWF, and they offered to assist me.
Once I arrived in Bangalore, India I called the Bangalore branch of the Working Woman’s Forum (WWF) and set up an appointment with Dr. Indrimma. The Bangalore branch is located in Vijayanagar, which is one hour away from the city center. Dr. Indrimma is an important figure at the Bangalore Branch of the Working Woman’s Forum. Though not the main focus of my research project, the Working Woman’s Forum is linked with my research for their involvement with the poor and their micro financing, which indirectly relates to the poor women I worked with. The Working Woman’s Forum is the vision of an unparalleled and humble Dr. Jaya Arunachalam. The core concept is that the poor are entitled to their rights in terms of organized social platform, access to credit, education, health care, and all the other basic services. Key to this organization’s success lies in its facilitation of a “bottom up” approach in its organizational efforts, in contrast to the majority of organizations and programs in India that are a “top down” approach such as DOTS. Additionally, the Forum encourages group structures, transcending barriers of caste, gender, and religion which are not just written on paper, but also actually implemented and programs that reach and work for people. This is a near impossible feat to achieve in India, and very commendable that this fabulous organization gets it right and excels at this. The Working Woman’s Forum set up and brought me to DOTS centers. The WWF is a well respected NGO in the area, among poor women, and has received international attention for their work. I believe that it made a difference being introduced by a well respected NGO to the hospitals and in obtaining government permission to carry out my study, legitimating me by being backed by a well respected NGO. In addition, the core concept matches my viewpoint and facilitated my interactions with the WWF. With out their kind support and their excellent knowledge of Bangalore, excellent negotiating, values, and people skills, my project would not have amounted to anything. With in the first couple of days I was set up with a hotel room, a woman from Chennai Branch named Sudah came and helped me with everything. It was an honor to have Dr. Arunachalam come personally to make sure everything was in order.

I saw one DOTS center before the Sriramapura Hospital. At the Sriramapura Referral Maternity Hospital, I spoke with the doctor on duty and he agreed to let me carry out my research there. This was the hospital’s first experience with a researcher but a foreigner as
well. I decided to carry out research here based on the existing DOTS center and relative small size of the facility. The dispensary is part of a larger network of TB programs in Bangalore and is not a major dispensary. I was granted four weeks with formal permission. I desired a place that was not too big scale, given the short-term nature of my project. Additionally, Sriramapuram is a relatively short distance (roughly 10 Kilometers) from the Working Woman’s Forum, Bangalore. The commute to the hospital, which was 10 kilometers away from the WWF, takes in the morning, under normal conditions, about 10-15 minutes by auto-rickshaw. There was construction and traveling to the hospital would take between 30-50 minutes each morning by auto-rickshaw. Getting a rickshaw from Vijayanagar to Sriramapura was difficult as, they are building a bridge in the middle of the main stretch of road. Thus, there are traffic jams through out the whole day and in particular the morning hours between 8am and 10 am.

I began research with out a translator, having Sudah act as a translator until the Working Woman’s Forum helped me to find Roseline. In the first week, I encountered a barrier. The doctor, who had given verbal and not written permission, asked us if I had gotten formal permission to research here. Baffled because I thought the all-clear signal had been given, I asked what he meant. He explained at the end of the day that I needed to get official permission from The Bangalore Mahanagara Palike (BMP). BMP is the name for the Bangalore City Corporation and represents the third level of Government in India. I returned to the WWF highly concerned. That day I obtained an interpreter. The next day we set out to get permission. With the full support of the WWF, Indrimma, Sudah, Roseline and one more women accompanied me to SRMH. The same doctor confirmed I needed official permission. Without stopping for lunch, we went directly to Bangalore Mahanagara Palike. We met first with Dr. Ramakumari, B.R., Project Coordinator RNTCP, she listened to my project aims and referred me to the woman in charge, Dr. Vijayalashkmi, Health Officer who oversees all TB programs in Bangalore. All five of us went to Dr. Vijayalashkmi’s office. She was very gracious and gave me one months permission to conduct field -work, this was a kind gesture as we came during her lunch hour and interrupted her lunch. Official permission can be a painfully long process, and I was extremely fortunate and extremely grateful to obtain permission the same day.
Having gained a stroke of luck and an interpreter, I was ready to officially begin (again)..

Depending on who had time and who wanted to be interviewed, patients would wait on the
bench and I would ask them to come into the room, the hospital directors’ office I was
allowed to use. I explained the interview to the women and if they wanted to stay they
could stay and if not they could freely go. It took me about two weeks to be recognized by
all staff and TB patients. After the two-week period, I was now a familiar face in the
hospital and women would acknowledge me with a smile or sit next to me. The security
guard greeted me each morning after two weeks and at that point, I was integrated into the
hospital. I became the friendly foreign face at the clinic.

1.3 Problem Statement

With severe social and economic consequences for women, and no gender focused TB
program, it is of the utmost importance to research the health seeking behavior of women
in Bangalore, India when faced with Tuberculosis. The health seeking behaviors and
perceptions attached to TB have not been measured in a health care setting in Bangalore,
India. Therefore, it is necessary to research how having Tuberculosis affects women in
Bangalore. The gaps in research, especially anthropological research, make it necessary to
look at health seeking behavior in relation to socioeconomic factors, gender, and adherence
to DOTS programs to gain insight to women’s health seeking behavior. It is necessary to
gain insight to women’s health seeking behavior so we can better treat the women who are
in DOTS and develop a gender-sensitive program. We need to know what their health
seeking behaviors are so we can see how the choices they make are shaped by their illness,
economic standing, culture, and the structure of the program. With this, we can better help
the women with tuberculosis.
Chapter 2

Literature Review

2.1. Background

India has a long history of Tuberculosis. India comes from a history of hierarchical structure with the caste system and imperial rule. Thus, India has had many impositions on its culture and its society. India has had the dubious distinction of having gone the farthest translating the holist, corporatist vision into reality. The dominant Hindu conception of a good society has always sanctified hierarchy over equality, duty over rights, and an undifferentiated, mystical unity over individuation and separation (Nanda 2003:16). With a country with a high population and low economic standing, it is logical that programs developed to combat TB could take some time to implement fully, and even replicate societal constructs. Let us now look at the TB programs.

Starting in 1958, the government initiated the National Tuberculosis Program (NTP) in Karnataka, India (Fox 1990:176). The Revised National Tuberculosis Program (RNTCP) replaced the NTP in phases beginning in 1997 (Sahni 2003: 102). Since 1993, DOTS (Directly Observed Treatment, Short Course) has been pilot tested in India as the Revised National Tuberculosis Control Program (RNTCP)(www.tbcindia.org/Key.asp). Though the RNTCP was originally a pilot test, it is being implemented in all of India. The RNTCP was originally a five-year project and was scheduled for completion in 2002 but was further extended for completion in 2004 (Shani 2003: 102). According to the Directorate General of Health Services, Ministry of Health and Family Welfare, RTCP is being implemented in the phased manner in the country. It was estimated that by December 2003, more than 75% of the country had been covered under DOTS and the entire country will be covered by 2005 (www.tbcindia.org/Key.asp). Currently it is not possible to determine whether this has been implemented completely and the WHO (2001) map shows less than 10 percent of
India being covered by Dots\textsuperscript{4}. Nevertheless, the RNTCP is a 100% centrally sponsored project and the project costs are reimbursed to the Government of India by the World Bank (Sahni 2003: 102).

The four main objectives of the National Tuberculosis Program were:

1. To formulate an applicable, acceptable and economically feasible national program for tuberculosis,
2. To train the necessary manpower to organize and manage the program,
3. To continue research with emphasis on operational activities to evolve the program,
4. From the late 1970s, to monitor the National Tuberculosis Program (NTP) (Fox 1990: 176).

The objective of the RNTCP is “To cure 85% of all sputum smear positive patients of tuberculosis detected in the program and to detect 70% of the estimated incidence of smear positive TB cases (Sahni 2003: 102)”. According to the World Health Report (2003) India ranks in 112\textsuperscript{th} position among developing countries (Narayan 2002: 3).

Unlike western countries, where a more or less efficient system of prevalence and incidence has existed for a long time, India has lacked in even approximate data about the prevalence and incidence of tuberculosis infection, disease, and mortality rates (Gothi 1982: 134). The earliest report on prevalence of infection in India is by Ukil in 1930, which found the observed rates were much higher in the urban areas (Gothi 1982: 134). One of the earliest official documents in which data regarding tuberculosis have been given is the Bhore Commission Report, 1946 (Gothi 1982: 134). The general impression at that time was that tuberculosis was mainly an urban problem and that younger persons, especially females, were more prone to it than others (Gothi 1982: 134). This seems to be the case today, as most studies on TB are conducted in highly populated urban areas, but few have focused on women. Females could be more prone, due to their role in the home, but little substantiates this statement.\{FIND CITATION FOR THE MEN\} In India, practically no reliable data were available till the early fifties about the prevalence or

\textsuperscript{4} See Appendix, Chart A
incidence of tuberculosis (Gothi 1982: 135). One of the earliest estimates was based on
findings of a small scale survey in the suburbs of Madras city (Chennai), which placed the
total number of active TB cases in the country at about 25 lakhs⁵, the estimated total TB
mortality in a year being of the order of 5 lakhs (Gothi 1982: 135).

We can see that since the late 1950’s the RNTCP and DOTS have been placed into effect
in India. One study in India, conducted by the Tuberculosis Research Institute, Chennai,
(TRC), Tamil Nadu, have examined the role of gender in TB but did not include economic
status (Morankar and Weiss 2003: 149). Others focus on the poor or leave out economic
status and gender all together. Though the urban population in the country has some
“obvious advantages (Banerji 1993: 71)” when compared to the rural population (Banerji
1993: 71). When these “obvious advantages (Banerji 1993: 71)” are compared to urban
women, women have some ‘obvious disadvantages.’ By looking at the burden of disease,
this becomes clearer.

2.1a. Burden of Disease

Looking at the burden of disease indicates the ‘whom’ and ‘where’ a disease is most
prevalent. The higher the numbers, the bigger the problem. The global burden of
tuberculosis is such that nearly one-third of the world’s population⁶ is infected with the
tuberculosis bacillus and at risk of developing active disease. This means about 8.4 million
people develop active TB every year and 2 million die (Blanc et. all 2001:9). Tuberculosis
accounts for 2.5% of the global burden of disease, or 26% of preventable deaths, and is a
leading infectious cause of death among young women (Blanc et. all 2001:9). Globally,
more than 14 million cases of TB exist and 3.5 million of these are infectious. TB is
responsible for the greatest mortality of any diseases in India. Inadequate ‘adherence’ to
effective treatment regimens remains a problem, and only 60 percent of the diagnosed
cases are cured (Sahni 2003: 190). The Directorate of Economics and Statistics (2000-
2001) states that there are seventy-seven Bangalore Hospitals and dispensaries and thirty-

⁵ One Lakh = 100,000
⁶ In 2002, global population stood at 6.2 billion (US Census Bureau 2004)
Historical experience has shown that when the overall annual risk of tuberculosis infection was high, it affected women who were aged 15-44 most (WHO 2002). Indeed, Tuberculosis is reported to be the single leading infectious cause of death in women worldwide (WHO 2002). TB kills over one million women every year. In 1997, TB killed 750,000 in the South-East Asia Region (SEAR), which India is a part of. Approximately half a million female deaths in the in this region in 1997 were caused by TB alone. Nearly two-fifths (38%) of the estimated eight million tuberculosis cases worldwide each year are from countries of the South East Asia Region (WHO 2002). The 1961-1968 Bangalore study is among the few to examine tuberculosis case fatality by sex (WHO 2002). Females aged 5 to 24 years had a fatality rate, which was 27-41% higher than males of the same age group (WHO 2002).

In India, tuberculosis was the leading cause of death of women in the reproductive age group, according to data for the 15-year period from 1981-1994 which was compiled by the Registrar General of India (WHO 2002). Tuberculosis poses a particular challenge because of its rapid spread in recent years, primarily due to co-infection with HIV/AIDS and the emergence of drug-resistant strains (WHO 2002). Clearly, women are at risk and tuberculosis becomes a direct threat to their survival and carries heavy social consequences. With such a high burden for women, we should hope they have somewhere to go for treatment. Looking at services available can help answer this question.

2.1b. ‘Availability’ of Services

Services are important to someone to have if they have an illness or say, TB. A person need to be treated. Bangalore is a large city in South India, so its chances for services might have a higher probability of existing and people being treated, given the larger numbers than say a rural area. Banerji (1993) agrees. The urban population in the country has some “obvious advantages (71)” when compared to the rural population for example,
concentration of the population, better civic facilities, a higher per-capita allocation for health services, and a large private sector of medical care (Banerji 1993: 71). However, presumably because of these very advantages, there is a considerable waste of resources due lapses in the organization and management of the health services as I illustrated with the programs for tuberculosis (Banerji 1993: 71). “In fact, despite the advantages, urban services are in a state of chaos causing problems to the people who seek alleviation of suffering (Banerji 1993: 71).” The poor, as usual, suffer the most (Banerji 1993: 71).

It has been widely documented that services fail the poor (see Jha 2003, Farmer 1996, Rodionova and Surti 2002, Devarajan & Shah 2004). Governments devote about a third of their budgets to health and education. Public spending is typically enjoyed by the non-poor (Devarajan & Shah 2004). Based on 1991 data for all of India, of the countries total hospital beds (810,000), currently 32% belong to private sector corporate hospitals. The private sector, in fact, employs nearly 80% of the country’s medical personnel (endnote ii Purhoit 2001: 94). Karnataka State has the largest number of medical schools in India and there is a surplus of qualified medical practitioners. Since opportunities for employment of these doctors in the government sector is limited, a large number set up practice in large villages and small towns (Bhatia and Cleland 2001: 6). Though low-cost services and free services exist, particularly in government hospitals, almost all segments of the Indian population bear some direct out-of-pocket expenses for the utilization of the health care services (Ellis, Alam and Gupta 2000: 212). The lightest burden being borne by workers in the public sector or those employed in large private firms (i.e. those well above the poverty line). The heaviest burden is borne by the people engaged in non-formal rural and urban activities (i.e. those poverty line or below) (Ellis, Alam & Gupta 2000: 212).

Despite the fact that TB treatment is widely available and often provided free of charge, it might not reach those that need it. In addition, knowledge and attitudes may vary among deprived communities in different parts of the country. The poor in urban slum areas and remote rural areas may have different understandings of TB as a disease (WHO 2005: 26). Even government employees with other forms of coverage bear considerable out-of-pocket expenses because they use private facilities and pay for drugs and services, which would
otherwise be cost free (Ellis, Alam & Gupta 2000: 212). TB is a serious concern in India and though much has been implemented to combat and stop this disease, still it seems it is not enough.

In Chapter 1, I have introduced the setting, methodology, and population I worked with and how I got there. In Chapter 2, I provided the necessary background information to set the stage for the rest of this work. I described a historical overview of the tuberculosis programs, the high burden of disease that especially effects women of childbearing age, and the programs that are ‘available’. In Chapter 3, I come back to the point of Indian society, namely the structure of Indian society. This has an overarching impact on the type of programs that are developed and the way they are implemented and is reintegrated throughout this work. I start out with an overview of a woman’s typical day and introduce the DOTS workers so we can immediately have insight into setting. Next, I convey the pervasiveness of injustice which includes the cost of health care, socio-economic factors, and structural violence. Structural violence in particular is a pervasive theme throughout this work. In Chapter 4, I discuss stigma. Stigma is a result of factors like structural violence, socio-economic factors, and gender. This can be seen in efficacy, silencing of this disease, and whom women talk to. This is highlighted by a case study of Kamala in Yamini. Chapter 5 I highlight these factors more by providing a case study on Sonia who experiences the full range of stigma. Chapter 6 focuses on the interconnection between agency, gender, and power. This comes into play with what motivates (or does not motivate) women to seek treatment. I highlight this with a case study of Yamini, who tells us her decision making process. Chapter 7 covers the women’s perception of the body. I discuss explanatory models, which illustrate their view of health and illness and relate this to TB. Chapter 8 focuses on the medical staff and their view of TB to compare viewpoints. We look at the biomedical view, which reinforces the differences between women and health care providers. In Chapter 9, I discuss the symbolic nature of the DOTS program and food consumption as a way women regulate their bodies. We see what the women view as good food and how the DOTS program intertwines the symbolic element and learn what inadequate ‘adherence’ to effective treatment means. In Chapter 10, I conclude and I offer some suggestions that can be applied. There is considerable overlap
Chapter 3

The Pervasiveness of Inequality

3.1 A Woman’s Typical Day

Indian women in the home are especially vulnerable to infection as family providers of health care for ailing in-laws, husbands, and children with TB (Morankar and Weiss 2003: 149). In addition, she must return for regular follow-ups when the household demands on her services always take priority; and accept that many drug side effects as normal (Shatrugna 1994 in Saha, & Ravindran 2002: 7) Prompt medical care to women infected with TB may be compromised. Women in many countries have to overcome several barriers before they can access health care. Women undertake multiple roles in reproduction, production and child care, they may be left with less time to reach diagnostic and curative services than men (WHO 2005:27).

A typical day of a women starts at 6am and ends at 10 or 11 at night. From when she wakes up, a women must cook (sometimes for ten people) breakfast, lunch, and dinner.
She must also wash clothes, bathe herself and children; pack lunches for herself if she works, her husband, and children if they are in school. In addition to cooking and washing, she must also clean the house; tend to a garden if there is one; run errands such as getting food, firewood, water (if there is no running water); take care of the children; and maintain harmony in the home with the in-laws (if she has them). This is unpaid work. Though, some women may not be responsible for the entire household. Her mother-in-law may expect the woman to do all the work except cooking. When all this is finished, the woman can go to bed and start again the next day.

For paid work, a woman must both finish all household work by 8am and go to work, or it could wait for her if she comes back. In most cases if her husband works too, he will not assist in the day-to-day chores. A typical workday for women starts around 8am or 9am and ends around six. Women work six days a week, sometimes seven. One woman got two Sundays off in a month. Coming to receive DOTS treatment is a little like a third job. For those women who I spoke with, they came at a lunch break and returned to work. These women must return for regular follow-ups when the household demands on her services always take priority.

Indian women in the home are especially vulnerable to infection as family providers of health care for ailing in-laws, husbands, and children with TB (Morankar and Weiss 2003: 149). Prompt medical care to women infected with TB may be compromised. Women in many countries have to overcome several barriers before they can access health care. Women undertake multiple roles in reproduction, production and child care, they may be left with less time to reach diagnostic and curative services than men (WHO 2005:27).

3.1a A DOTS Worker’s Day

Now lets meet the workers at the hospital. One is the Laboratory Technician named Mohan. Mohan is responsible for DOTS7 and starts his day at the hospital at 9am. He is

7 See Appendix, v, Image 2
from Bangalore and who joined the hospital eight years ago. He joined to help the patients. Mohan has a friendly demeanor and is approachable; patient, and works very hard. Patients are constantly seeking advice and treatment. He has a clearly defined role and is responsible for:

- Blood investigation, sputum examination, and dispensing the tablets out; DOTS; Monday, Wednesday, Friday

There are currently 70 TB patients and additional maternity patients.

Saravanah is the Health Visitor and lives in Bangalore. Saravanah is a very dedicated and friendly man. He is very pro-patient and always willing to help. During the interview, he received a phone call from a patient on a Saturday. Saravanah studied health inspection, and for the past seven months, has been working as a Health Visitor for the RNTCP. He works with about 100-150 cases in three centers and is spread thin, with calls coming in throughout the day at all hours and is usually busy. I asked him what he does when he comes to work to when he leaves. He comes in at 9am, and though the hospital is open until 4pm, he stays until 4:30,

Because I give my phone number to people, so they’ll call late, 8 o’clock or 9. Otherwise, my working hours they’ll call me so I have to go visiting in those hours also. Apart from patients my working duty, hours working extra hours like that.

When Saravanah comes in at nine, he will check the treatment logs,

I’ll see there are TB patients who have come, who have not come. So, I’ll see that if they have not come to take their tablets. I’ll go search them to their houses” he will ask them “why you not come today on DOTS day?’ why didn’t you come to take the tablet?

8 Other days --Tuesday and Thursday-- he is responsible for the maternity patients. Though there are designated days, I saw him consult a maternity woman who had made the effort to come on a DOTS day. Mohan explained what he does for the Maternity patients.

“Maternity. The blood investigation, hemoglobin, glucose, urine sugar, urine microscopy, and then HIV test. Monday and Friday. Alternate antenatal days Tuesday Thursday”.

28
He does this every Monday, Wednesday, and Friday. His phone rings on the days he is not at the maternity hospital, for he is the health worker for two other dispensaries. Now that we have been introduced to a women’s day and the health workers day, we can see that both are very busy. I introduced both together because they have many interactions with each other and are part of the same society. The rest of this chapter focuses on women and injustices in society. My aim is not to make the health workers appear unaffected, for they are in the same society and system as the women and subject to the same injustices. I am also not trying to ‘victimize’ women or ‘demonize’ the health care workers. The women as we know are the focus of the study and I aim to present the results of my research with the pertinent factors, presenting a holistic picture.

3.2 Show me the Money, Money Spent on Health Care

Which such high figures for women in the South East Asia Region, which encompasses India, interestingly enough, the only study I found including gender, tuberculosis, and anthropology was Morankak and Weiss’s (2003) study. This took place in rural Pune District, Maharashtra, in North India. The main results were similar to my project but did not provide an in-depth analysis. Their study was similar in that, Women patients were driven out by in-laws and were taking treatment in the homes of their own parents. Typically, the in-laws treated these women normally until TB was diagnosed. Patients treated in natal homes received care from parents, while women living in joint families reported that apart from their husband, no one else in the family was aware of their disease. They feared the consequences if other family members were to find out about their disease (Morankar and Weiss 2003: 150). What it did not talk about was money spent on health care.

Information on health expenditure suggests that in most poor countries, like India, the private sector is an important source of care (Uplekar, Pathania, & Raviglione 2001: 912).
Managers of tuberculosis programs believe that only a small proportion of tuberculosis patients (mainly the well of) seek care from private practitioners. The basis for this assumption is that tuberculosis mainly affects the poor who cannot afford private doctors’ fees and expensive drugs. (Uplekar, Pathania, & Raviglione 2001: 912). Though the poor are mainly affected by TB in India, the women I spoke with, also visit a private practitioner. However, due to financial limitations of poverty, they cannot afford long-term fees and drugs. After consulting with a private doctor, they follow with government hospital care. This trend shows that the women, though they may not be able to afford to continue visiting a private practitioner, they utilize private practitioner services. Table 1 includes the 12 women who participated in my research, illustrates what they spend on health care.

Table 1: Money Spent on Health Care

<table>
<thead>
<tr>
<th>Participant</th>
<th>Private Practitioner</th>
<th>Government Doctor</th>
<th>Income Per Month</th>
<th>Insurance 1/Yes/ No</th>
<th>Extra Money Food</th>
<th>Total (Rupees)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Not reported</td>
<td>Not reported</td>
<td>None</td>
<td>No</td>
<td>No</td>
<td>Unknown</td>
</tr>
<tr>
<td>2</td>
<td>Not reported</td>
<td>0</td>
<td>+/-2500 if employed (46 EURO)</td>
<td>No</td>
<td>No</td>
<td>Unknown</td>
</tr>
<tr>
<td>3</td>
<td>Rs.6,000</td>
<td>0</td>
<td>1000 when working</td>
<td>No</td>
<td>No</td>
<td>Rs.6,000 (112 EURO)</td>
</tr>
<tr>
<td>4</td>
<td>Rs.11 for 8 tablets x 2 years</td>
<td>0</td>
<td>600/mo (11EUR)</td>
<td>No</td>
<td>No</td>
<td>Rs.(+/-) 7,000 (130 EURO)</td>
</tr>
<tr>
<td>5</td>
<td>Not reported</td>
<td>Not reported</td>
<td>5000/mo (93 EURO)</td>
<td>No</td>
<td>No</td>
<td>Unknown</td>
</tr>
<tr>
<td>6</td>
<td>Rs.70 consult &amp; tablet cost*</td>
<td>0</td>
<td>Student</td>
<td>No</td>
<td>No</td>
<td>Rs.1,096 (20 Euro)</td>
</tr>
<tr>
<td>7</td>
<td>600/1 week</td>
<td>0</td>
<td>Not reported</td>
<td>Husband, accidental insurance, she ESI***</td>
<td>No</td>
<td>Rs.600 (20 EURO)</td>
</tr>
<tr>
<td>8</td>
<td>0</td>
<td>0</td>
<td>3-4000/mo (56-74 EURO)</td>
<td>No</td>
<td>No</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>1000/year</td>
<td>0</td>
<td>2000/mo (37 EURO)</td>
<td>Husband has work insurance</td>
<td>No</td>
<td>Rs.1,000 (18 EURO)</td>
</tr>
</tbody>
</table>
Participant 10 | 0 | 0 | 5000/ mo. (49 EURO) | Life insurance 1700 premium each 6 mo. | No | 0
---|---|---|---|---|---|---
Participant 11 | 0 | 0 | Varies month to month | No | No | 0
Participant 12 | 0 | 0 | Not reported | No | No | 0
Total (Rupees) | Rs.15,696/ 293.54** | 0 | 0 | 0 | 0 | Rs.15,696 293.54/ EURO

* Tablets cost Rs (Rupee) 15 for 2 months then 9 for four months
** Euros (EURO), in 2005, 1 Euro=53.4702 rupees (www.xe.com/ucc)
*** ESI= Employee State Insurance

Five women spent money on a private practitioner or money on tablets. These women earn between 11 Euros- 46 Euros a month ($49-$123 US Dollars) (www.xe.com/ucc). The women visited the private practitioner first and then went to the government hospital.

3.3 Relation to Poverty

The average income of a person per month in India is approximately 160 Euros a month ($200 US Dollars), which has 25% of the country below the poverty line as, estimated by the CIA in 2000 (www.odci.gov/cia/publications/factbook/geos/in/html/#Econ). The Copenhagen Declaration describes absolute poverty as “a condition characterized by severe deprivation of basic human needs, including food, safe drinking water, sanitation facilities, health, shelter, education and information” the World Bank defines “extreme poverty” as people who live on less than $1 a day, and “poverty” as less than $2 a day. This means that 21% of the world’s population in 2001 was living in extreme poverty, and more than half of the world’s population was poor (http://encyclopedia.laborlawtalk.com/poverty). Thus, with these definitions, the women fall under the ‘extreme poverty’ to ‘poverty’ levels of income.

As nearly all the private spending is out-of-pocket, the poor are highly vulnerable to health risks. This leads the poor to seek treatment from a government hospital, which provides free services. Women prefer a private practitioner because they spend less time waiting to see the doctor, they get faster service and can get back to the home faster. At the government hospital, they complained of the quality of care, long waiting periods and low
quality drugs prescriptions. I have illustrated that the women that reported their income, fall either in extreme poverty or at the poverty line. If there is a medical situation that needs to be paid for, unfortunately they cannot economically cope with this situation.

The poor generally avoid hospitalization because of their inability to pay (Narayan 2002:15). Women I interviewed tried to avoid hospitalization in general. To be hospitalized in either a Private hospital or a Government hospital frequently means financial disaster for two reasons. First, if the woman is hospitalized she or her family will most likely not be able to pay for it. Secondly, the poor can literally not afford to be sick. Hospitalization means forfeiting a day’s wage, and spending more than they earn for one day’s hospitalization. If a working family member must be present at the hospital, two wages may be lost. If there is not money being earned on a daily basis and only money being spent, it places them in an economic crisis. Furthermore, Indians do not have insurance to cover their hospital stay. As the World Bank document shows, only 10 percent of Indians have some form of insurance, and most of this is inadequate (Narayan 2002:15). Of the 12 women I spoke with, only one had insurance, Employee State Insurance (Table 1). Hospitalized Indians spent more than half (58%) of their total annual expenditure on health care, more than 40 percent of those hospitalized borrow money or sell assets to cover expenses, and at least one quarter of hospitalized Indians fall below poverty line because of hospital expenses (Narayan 2002:15). We can see that there is a direct relation between income, illness, hospitalization, and poverty. Though women may prefer private to government practitioners, the socioeconomic conditions create a barrier to health care.

3.3a. Socio-economic Factors

It can be argued that the real cause of the spread of TB is not so much the microbe as it is socioeconomic and political factors outside the human biology. Socioeconomic factors affect a person’s vulnerability to contracting TB and limit their access to treatment, especially women (WHO 2001). While anyone can contract tuberculosis, we see that the marginalized, discriminated against populations, and people living in poverty are affected
the most (WHO 2001). Compounding this problem in India are economic, geographical, socio-cultural and health system barriers. There is considerable overlap and interdependence between the barriers in each category (WHO 2005: 22).

These are mainly due to six main socio-economic factors. These are

1. Over-crowding,
2. Low income,
3. Poverty,
4. Public assistance,
5. Unemployment,
6. and education (Gupta et al 2004: 30).

Together the socioeconomic factors and the high prevalence of Tuberculosis add up to a sizeable problem. India has a high population, which leads to overcrowding, be it at the level of the household or a city. Thus, geographically, overcrowding leads to increased risk of disease transmission due to the close proximity in which people live (Gupta et all 2004: 30). Some of the women lived with to 10 members or more in a household. Though these women may not be solely responsible for the income in their home, income, especially for those living in poverty, is another troublesome factor. Worldwide, over a billion people live in absolute poverty and 75% are women (WHO 2005:22). Poverty may also result in poor nutrition and body weight, which makes the immune system more vulnerable to disease (Gupta et all 2004: 30) and more difficult to access the health system. Unemployment also affects barriers to health systems and economic position. In 2004, unemployment was reported to be at 9.5%. India’s economy is mostly dependant on agriculture, industry, and the service sector (http://en.wikipedia.org/wiki/Economy_of_India#Notes). Education is relatively low and India's literacy rate is 64.8%, with 53.7% of females being literate in 2004 (http://en.wikipedia.org/wiki/India). Most of the women I spoke with ended school at the age of 14, or had completed up to some college.

To highlight these barriers, the living arrangements of the women can help us to understand the context in which they live. It is important to look at the arrangements because this can
affect the access to health and economic resources and how this affects women.

Table 2: Woman's Living Situation and Marital Status

<table>
<thead>
<tr>
<th>Women’s Living Situation</th>
<th>No. of Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married, Living With Husband</td>
<td>2</td>
</tr>
<tr>
<td>Separated, Living With Natal Family (because of TB)</td>
<td>4</td>
</tr>
<tr>
<td>Married, Husband In Different State</td>
<td>1</td>
</tr>
<tr>
<td>Abandoned By Husband (not because of TB)</td>
<td>2</td>
</tr>
<tr>
<td>Not Married</td>
<td>3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>12</strong></td>
</tr>
</tbody>
</table>

As table 2 shows, four of the women are separated from their husbands and living with their natal family. We have reviewed their income (Table 1) and see they are in a precarious position regarding their health, social, and marital situation. The economic implications for the natal family can be devastating because they did not plan to have an additional person to feed in the house. This can further constrain already scarce economic resources. None of the women that live with their parents are officially divorced. They are separated because they have TB. Three of the families with their married daughters home, had paid a dowry, which will not be refunded if the women stay separated. If they want their daughter to get remarried, they will likely have to provide another dowry. The two married women living with husband and the women with her husband living in a different state, do not live in a joint family. The women who are separated and living with natal family previously lived in a joint family. Of the women abandoned by their husbands and do not have any parents. The women who are not married live with their parents and do not work outside of the home. Five of the women work full time and one is looking for a job. Despite the living arrangement, the important point is, the economic situation negatively affects women. The fact that some are not separated from their husband does not indicate a favorable situation. Though five women work, their economic woes are compounded by having TB.
3.3b. Structural Violence

What we are really talking about here is Structural violence. The above are all illustrations of this in Indian society. Though structural violence is called other things like ‘poverty’ ‘lack of resources’ ‘socioeconomic factors’ ‘barriers’ and ‘gender’ the main point is the condition of lack of access at the structural level results in negative consequences for society members. This mirrors the hierarchical structure of Indian society and its negative impact on women, as I pointed out earlier. A society that grants the powerful, unequal, or exclusive access to positions of leadership, jobs, decent housing, education, health care, and nutrition is called “structural violence” because of its insidious and deterrious effects on marginalized communities who are usually the most economically underdeveloped (Coleman 2003:16).

“Structural violence” as stated by Paul Farmer (2003) points to influences of “the nature and distribution of extreme suffering (xiii)” Farmer (2003) argues that,

> Human rights violations are not accidents; they are not random in distribution or effect. Rights violations are, rather, symptoms of deeper pathologies of power and are linked intimately to the social conditions that so often determine who will suffer abuse and who will be shielded from harm.

To bring this point home, in India, the richest fifth receives three times the curative health care subsidy (Peters et al 2003:218 in Devarajan and Shah 2004: 908). Public spending can be reallocated toward poor people but the money does not always reach and subsequently, the poor in dire need of the services (Devarajan and Shah 2004: 908). The impact of a [lack of] public spending reaches the doctors, medical staff, and nurses who are caught in a system where the incentives for effective service delivery are weak and sometimes remain unpaid for their services (Devarajan and Shah 2004: 908). Women have little to rejoice about. The National Policy for the Empowerment of Women in India (2001) was ‘a great achievement’ in the history of Indian women’s human rights( Ghansham 2002: 2). This ‘great achievement’ amounted to little more than a paper law that is overlooked and has not improved women’s rights, at least for the women still paying dowry. Yet, gender bias is traditional in India, with some states noted for female infanticides and female feticides. The
incidence of female feticide is rising due to traditional son preference and intrinsically linked to the dowry system, which has technically been illegal since 1961 thanks to The Dowry Prohibition Act, 1961 (Ghansham 2002: 2) but still practiced today.

One of the main reasons (which includes structural violence) underlying the poor state of health care facilities in India happens to be the very low levels of public expenditure in the health sector, which happens to be among the lowest in the world. During the decade of the 1990s, it became even worse as the public investment on health as a percentage of GDP declined from 1.3% in 1990 to 0.6% in 1999 (Jha 2003: 17), compared to Germany, which had the highest public expenditure in health at 8.3% (Jha 2003: 54). As I illustrated earlier structural violence can be seen many places. When the women were asked, “what did you think was the problem before you found TB came to you” it may not seem surprising that it wasn’t just TB. Women are aware of their position. Structural violence at the level of society, family, gender, and health care, are ‘barriers’ for these women. Another outcome of this injustice is stigma. Stigma effects women more than men and results from family members and other members of society finding out a women has TB.
Chapter 4

The Stigma Experience

We have seen the interconnection between structural violence, Indian society, and its effect on women. While anyone can contract TB, the marginalized, discriminated against populations, and people (mostly women) living in poverty are most affected (WHO 2001). Stigma has a double marginalization and discriminating effect of women. Women in India are already marginalized, discriminated against, and mostly live in poverty. A woman with TB is subject to double the discrimination, marginalization, and stigmatization due to being a woman, and having TB. The consequences of stigma, as we will see, are severe for women. These include mockery, (forced) separation and/or divorce from husband, separation from children, and moving to her natal home from the in-laws.

4.1 The Context of Stigma

The history of stigma is culturally determined. Stigma has become a marker of unpleasant experiences like, shame, blame, secrecy, isolation, social exclusion, stereotypes, and discrimination (Byrne 2000: 65). Townsend (1979) explains that stereotypes are about selective perceptions that place people in categories, exaggerating differences between groups ‘them and us’ in order to obscure differences within groups (Byrne 2000: 66). Women are in danger of encountering stigma if someone finds out she has TB. If someone finds out, they are categorized as having TB. Stigmatization results and is a social reaction of those who do not have TB. In-laws share the same economic status, home, yet disassociate themselves with those that have TB. Women are very careful about who they tell if they have TB. The stigma is a result of social perceptions about TB. Figure 3 illustrates the characteristics of stigma which the stigmatized factors stem from structural violence in Indian society. TB, gender, and poverty are all related to each other.
Stigma has been defined by Goffman (1963) as “an attribute that is significantly discrediting” (Bond, Chase, & Aggleton 2002: 1). Gilmore & Somerville (1994) point out stigma is “an attribute used to set the affected person or groups apart from the normalized social order, and this separation implies a devaluation (Bond, Chase, & Aggleton 2002: 1). The ‘normalized social order’ is a subjective term which, for this work, means those in India with out TB and not living in poverty. Poverty line people are out of the normalized social order because they are poor, but separate themselves from those with TB by devaluing those with TB. This describes stigmatization, which is the process of devaluation within a particular culture or setting, where certain attributes are seized up on and defined as discreditable or unworthy (Bond, Chase, & Aggleton 2002: 1).

Merely having TB is not discreditable in itself because transmission of the disease is an invisible process. Rather who has TB is the discrediting factor. Once someone knows sees a person has TB, the person is socially labeled as having TB and separated from them. Women here bear the double burden of stigma and poverty. Since women and the poor are devalued in Indian society, it is socially acceptable to separate them from the normalized social order.
The stigmatized quality, according to Goffman, (1994) is “neither creditable or discreditable as a thing in itself” (Bond, Chase, & Aggleton 2002: 1). Poverty here is not the infectious disease, though a major co-factor in getting TB, rather poverty is seen by the people as an unwanted quality. Women often prefer not to have girl children, because they will cost the family too much (Ghansham 2002: 2). As Sachdeva (1998) points out, the status of women in India has been a chequered one as it has seen many ups and downs (Ghansham 2002:4). Gender has been discreditable for a long time in India. So, we can see that people do not want to be poor, women, or have TB.

It is unclear where exactly the stigma originated in the context of Indian society. Though there is fear of [greater] poverty, misinformation about what causes TB, how the disease is transmitted, and whether it can be cured is linked to the stigmatization of TB and of people with TB (WHO 2001). Poor resources dominate negative attitudes towards the poor from a structural and societal level. Finally, it is important to remember TB is deeply rooted in populations where human rights and dignity are limited (WHO 2001).

4.2 The Silencing of TB

Stigma greatly affects the women’s lives and affected their daily lives. Women make conscious decisions of whom they tell they have TB and not to tell because they are aware of the stigma. Women who told someone they ‘shouldn’t have’ (i.e. their mother-in-law, or husband) experienced the unpleasant stigma experience. Understanding stigmatization and discrimination as social processes can help us to understand that stigmatization and discrimination are not isolated phenomena, or the expression of individual attitudes. These are, however, social processes used to create and maintain social control and to produce and reproduce social inequality. Referring to Figure 3, we can see that these discriminating factors create a difference and social hierarchy. According to Geertz, (1983) stigma and discrimination are used to create “difference” and social hierarchy. Stigma is produced and used to help order society. For example, most societies achieve conformity by contrasting those who are “normal” with those who are “different” or “deviant”. Cultures produce “difference” in order to achieve social control, which tend to marginalize some people.
Reasons for marginalization of women have roots in the social system and cultural attitudes (Bali 2001:137). The structure of the Indian society as predominantly patriarchal, start women out with disadvantages that multiply over a lifetime (Bali 2001: 137). We can see the silencing process begin almost right from birth (or before birth with feticide).

Silence gives the women power and immunity from the stigma. In addition, silence can be attributed to an internalization of prevailing cultural attitudes, which in India, view women as inferior and see them as having only themselves to blame for their predicament. It seldom sees them as victims a form of oppression or of socially prevalent sex biases (Ghansham 2002:7). Women are aware of the prevailing cultural attitudes, know that inequality exists in their society, as they experience it first hand. By maintaining silence, they are working within the framework of society and using it to avoid stigma.

4.2a Who Women Talk To

The women stay silent to protect themselves from the social stigma as I have described in detail above. If the woman does not tell others she is sick with TB, her social and household responsibilities do not change. Someone may notice by a woman’s physical appearance she is not well. In this case, the woman will not divulge that she has TB. Rather, she will acknowledge her ill health by saying she is ‘not keeping well’(as we discuss in Chapter 7) with some ailment such as ulcer, cold, or fever. These illnesses are not stigmatized in Indian society and can be used repeatedly to explain their appearance. She must not make the public (usually a neighbor) or in-laws aware to avoid actual or perceived stigma consequences. If someone like a neighbor finds out, it will not remain a secret. Kamala and Yamini have kept silent about their disease. They have told only people they believe will not tell anyone else, like their husbands or natal parents and avoid disclosing information about their disease to anyone else.
Kamala is a twenty-seven-year-old woman born in Bangalore and is a mother of two children. Before marriage, she was a schoolteacher but quit her job after marriage to work inside the home. Three months ago, Kamala decided to move to her natal home. At the time of the interview, Kamala had been living at her natal home for one month and has been taking TB medication for four months. She pays 10 rupees a day, three times a week to get to the clinic by bus, which takes her a half hour or more. I asked what lead up to her decision to move to her natal home. Kamala went to the doctors for TB, but realized she had a long treatment period.

I told my [natal] mother and brothers but the husband I did not tell. They [in-laws] might mistreat me and not allow my children to come closer.

I asked her why she did not tell her husband.

Kamala: I feel, I feel that he might think, feel bad or he might mock at me or things [Allison: what kind of mocking?] Kamala: so they give some threatening and uh doing something uh my mother-in-law has done so I don’t stay. My husband, I might be ill-treated probably keep us separate from the family and even they might not allow my children to come close to me, so I am afraid. my child is very small, nine months, so I stay with my parents. [Allison: did you tell your neighbors?] Kamala: no [Allison: why?] Kamala: they talk [AW: did you tell anyone else you had TB?] Kamala: no

When I asked her what she thinks her husband would say, if she told him she had TB, Kamala responded:

There’s a threat I will feel. I will have to live separately. I would be banned from the family. I have been separated from the family in peace. In case, I have been separated. I moved because I didn’t want a problem
Kamala told her in-laws she had an ‘infection’ and moved out. She plans to return to her in-laws in four months. She circumvented the situation by moving out on her own accord because she knows that TB is a stigmatized illness and she wanted to avoid a problem and/or separation from her children. Though she moved out, this did not upset the family because she moved out in a culturally appropriate way. She enlisted the help of her mother who agreed to take care of her while she was sick. Further, this kept her marital situation intact and allowed her to stay with her children. Her husband visits her and anticipates her return home. When I asked her what would happen if her in-laws found out the truth, she did not wish to discuss it. Kamala moved to her natal home and avoided stigmatization, but not the threat or fear of stigma.

Yamini is a 55-year-old married woman who lives only with her husband and has no children. Yamini was married at the age of 40, which is late in Indian culture. Her elder sister and brother-in-law arranged the marriage because her parents are deceased. Her husband is currently employed and Yamini is a housewife/homemaker and works in the home. She and her husband do not have any children, for which people mock her (not her husband). Her husband is supportive as Yamini stated. “He accompanies me every day [to DOTS].” Her husband said:

Since we have no issues (children), our financial problem of education paying the school fees, it doesn’t apply to us. We are happy and content. (they move close to each other) she is a child for me, and I am a child for her.

The husbands view on happiness and contentedness is accepting the situation of not having children and his wife having TB and that he has someone to take care of. This is different from Kamala’s situation, as, Yamini does not live in an extended family or have children. So, she should have less to worry about, right? Not in this case. Yamini shares the same marginalized and discriminated position in Indian society as Kamala. Despite her husband’s acceptance of her condition, she will not tell anyone else she has TB. The point is there is a fear of stigma and women stay silent to prevent the effects of stigma. Yamini said,
I do not tell anyone I have TB, because normally I’m in the gossip because I don’t have a child. I feel incase I tell this problem they might mock at me and abuse me. They’ll mock at me.

The women simply do not speak up about having TB. Yamini was stigmatized for not having children and perceived more stigma for having TB so she said nothing, except to her husband. Kamala had the opposite situation. Kamala was not stigmatized for having children, but could have been stigmatized and separated from them had she disclosed that she had TB to her husband or in-laws. She said nothing to her husband or in-laws but told her parents she had TB.

4.2c. Social Efficacy

Yamini and Kamala were lucky to avoid the stigma experience but still are at risk of being stigmatized if anyone else finds out. There is not a sick role developed in the way Helman (2001) describes it. Helman suggests that the sick role that provides a legitimate channel of withdrawal from adult responsibility. The ‘sick role’ is a socially acceptable role of an ill person, in our case a women with TB. Those defined as such are temporarily able to avoid their obligations towards the social groups, such as family and friends. These groups often feel obligated to care for their sick members while they are ill (Helman 2001: 85). Women in this study, though they are sick, do not necessarily get care from their in-law family. These implications of caregiving are labeled ‘social efficacy’ to draw attention to the way that giving medicine works through suggesting something about the people involved (Whyte, Van der Geest & Hardon 2001:30).

After a women is married, she moves away from her natal family and in with her husband. The in-laws and her husband, replace her natal family are supposed to care for her and her needs. Marriages in India are usually arranged by parents and the wife becomes a member of the husband's family, in most cases moves in with them. The newly wedded bride is expected to switch her principal loyalty overnight to her husband's family (Natarajan 9 See Appendix, iv,Figure A
1995:298) The husband's family may make little accommodation to the bride, but expect her to adjust to them. Since they are now supporting her, the husband’s family believes that she must be considerate to their wishes. If they think she is not, they may feel justified in treating her harshly, even violently. This reflects the Hindu norm that once a girl is married, her parents have only limited rights to a say in her new family's personal affairs (Natarajan 1995:298). When a women has TB, there is a suspension of care from the in-laws. The woman is moved to her natal home by her in-laws or on her own accord. The in-law family makes little effort to accommodate the daughter-in-law or care for her while she is sick. They return her to her natal home and remove themselves from the situation. Since the daughter-in-law is now a member of their family, they are supposed to care for her. What we see here is the in-law family avoids obligation and sends the daughter-in-law back to her natal home. She must obey the in-laws, and move home, becoming the temporary responsibility of her natal family. Husbands do not always support their wives and, when her parents live at a distance and cannot easily come to support her, she is even more isolated (Natarajan 1995: 303). So, who is providing a sick role?

The medical system provides a sick role for the women. DOTS medication has provided the caregiving that the women do not get in their homes. Even if she moves home, she is a economic burden on her natal family. She is supposed to reside with her in-laws. A women moved to her natal home, suggests that the women are not taken care of at their in-laws homes. What we see here is the in-law family avoiding care of a sick family member due to the stigma associated with TB.

If the woman moves to her natal home, she is socially acknowledged she is sick through stigmatization. In this case, the in-law family is in control because they have done something about her condition. If a woman moves home in fear of stigmatization, she has taken control over her condition. In either case, the sick role is provided by the DOTS staff because women avoid telling certain family members they are ill and they try to work as usual without a disruption of their roles. TB is recognized as an illness worthy of care by the biomedical system, but not an illness accepted by the family or society. This point
is exemplified by two women and whom they tell if they have TB. Kamala and Yamini were very selective in who they told they had TB.

We are looking at the symbolic border between “attribution of blame to perceived vectors of infection, identification of scapegoats and victims, the role of stigma, although they are manifestly part and parcel of many epidemics (Farmer 1996:266).” Often, marginalized groups and the poor have limited access to information sources, so knowledge and messages promoting behavioral changes that help dispel stigma are not effectively disseminated (or disseminated at all). Where female literacy and education levels are low, the consequences of stigma may be particularly marked for women (WHO 2005: 26). Since TB is not a socially accepted disease, no full sick role is developed.

Nowhere is stigma more clearly illustrated as in HIV/AIDS-related stigma and discrimination. Stigma and discrimination take different forms and are manifested at three different levels:

1. Societal
2. Community
3. Individual

These three occur in different contexts (Parker, Aggleton et all 2002:4). The same can be said about TB and it happens to the women I spoke with. TB-related stigma and discrimination have been most frequently documented and where there is the greatest need interventions to reduce or mitigate stigma and discrimination (Parker, Aggleton et. all 2002: 4).

Women, in general, have less access also to public resources, such as education and health care. This is due, in part, because of state policies and partly because of social customs, which dictate that scarce resources go to men first, and boys and only later to girls and women (also known as structural violence) (Bali 2001: 137). Poor women with TB tend to suffer from fear of stigma, being rejected by the family, and the community. I have shown that the stigma of TB is very pronounced among women. Men usually worry more about loss of wages and capacity for work, women worry most about social rejection – from
husbands, in-laws and the community in general.(WHO 2005: 27). Bali (2001) states, “they are more likely to be malnourished starting as a result of relative deprivation of food and health care for girls as compared to boys and continuing with pregnancies, the process of lactation and over wok at physically arduous tasks such as collection of fuel and water (Chapman, 1992 xv-xvi quoted by Bali 2001: 137)”. Again, we see that this is structural violence. We have seen the major ways the stigma affects women which emerged in four ways:

1. Related to gender
2. Obtaining health care
3. Silencing
4. Absence of sick role

If someone finds out, she has TB, stigmatized, the woman is moved to her natal home. When she moves to the natal home, her parents will not stigmatize her further, but the woman has already become stigmatized where divorce negotiations may take place during this time. The sick role takes a twist and is shifted to the DOTS program, where they provide the social efficacy and define a role for their sick patients, where the families often do not. Women in India are already marginalized, discriminated against, and mostly live in poverty. TB is a disease that is highly stigmatized in Indian society. A women with TB is subject to double the discrimination, marginalization, and stigmatization due to being a women, and having TB. Merely having TB is not discreditable in itself because transmission of the disease is an invisible process. Rather who has TB is the discrediting factor. Stigma, gender, power, the underlying cultural norms, and structural violence merge to create this condition. Stigmas are socially constructed and partially arises from cultural norms about what a person should be and what people who deviate from the norm are (Bond, Chase, & Aggleton 2002: 2). This is illustrated by the sick role provided by the medical system and not the families. I illustrate this point next, through Sonia’s stigma.
Chapter 5

Sonia’s Stigma

Sonia is in her early 30’s who lives in Bangalore. Prior to marriage, she made about 46 Euros a month, which means she was living on about 1.50 Euro a day. Since marrying three months ago, she quit her job and she is now a housewife/homemaker. Sonia’s marriage was arranged. Her family paid 50,000 Rupees for her dowry, which is about 934 Euros. Dowry is now officially illegal thanks to The Dowry Prohibition Act, 1961, but still practiced. After marriage, she moved in with her mother-in-laws to husbands house, where she shares it with four other brother-in-laws. Three months ago, Sonia found out she had TB.

I was very surprised and I felt a person of my age would never have this, but then the doctor said the person has sputum, incase I had come in contact with something. That’s how it’s transmitted.

She used to cough and get a regular fever. She found out she had TB through an x-ray a doctor took because the sputum tests were negative. Sonia is very dedicated to her treatment and has never missed a day, she would even come on a religious holiday. When I asked Sonia what she thought the problem was before she found she had TB she responded,

I had a problem in my chest, suffering from breathing problem. On and off. Then I decided I’ll take a chest x-ray. One month.

After she was married, Sonia had pain in her chest and a breathing problem for one month. It was not until recently that she had a continuous fever for one week, that she sought a doctor. Sonia has been taking DOTS for two months. She was the only woman that decided to come to the hospital on her own accord.

I took the decision of coming here because my husband wouldn’t take me to any of the doctors. So, it was a bold decision I myself have taken and come out. I told him, but he neglected me.

Sonia had asked her husband to take her to a doctor for her chest and breathing problems, but he refused. Sonia recognized these symptoms as unhealthy but could not get the health
care she sought. Only when she had a continuous fever that did not abate that she decided to come to the government hospital because her husband refused to help her. When Sonia found out she had TB, she confided in her natal mother and husband, which was “more than enough”. She did not tell anyone else.

I asked Sonia if her mother-in-law said anything about her having TB, she casually alluded to they knew she was sick but not that she has TB. She stated that her mother-in-law asked her to move home a month ago.

Because its closer to the hospital so I can take regular visits to the doctor. The mother-in-law asked me to stay with my parents because of the medicine I need to take. (stated matter-of-factly) I visit my mother-in-laws quite often when I am taking medicine, but after taking medicine, I go to my birth place.

This sounds neutral enough and was presented to me rather matter of factly. When I asked if her mother-in-law said anything else, she responded “they mocked at me” and crossed her arms. Sonia was not mocked at this point for having TB, but for being ill. Sonia has decided to obtain a document stating she is cured from TB. Sonia needs a document, just like ten of the twelve women I spoke to. Sonia stated each answer flatly and matter-of-factly as she summarized what she was going through. Sonia illustrates,

I need a black and white letter that states I have been cured 100%. Cured 100% and there is nothing wrong in me. I need a letter I need a document. My mother advises me to go see another doctor to verify I have been cured 100%.

Sonia needed the paper because if they ever found out she had TB, she would have to prove that she was cured. Her mother suggested going to another doctor to verify that she is cured. The next week things had taken a turn for the worse, Sonia burst into the interview room announcing her mother-in-law found out she has TB. Sonia distraughtly explained,

Today I have a problem with my husband. They’re asking me to get healed for sure and then come home. I don’t like the advertising campaign of my mother-in-law. for my disease. Anyone who’s coming will say my daughter in law has got TB. She’s suffering from it. My mother in law tells everyone.
According to Sonia, her mother-in-law told everyone, even people she does not know that she has TB.

My mother-in-law is saying supposing someone comes home and they telephone they say ‘oh she’s got TB, suffering.’ ‘oh you’ve got TB’ ‘I heard, your mother in law told me.’ It’s the same news. Sometimes I feel let down. the same relatives who come to my house told. Even my neighbors don’t know me at my mother’s house. Then my relatives come and tell me. I feel sad. My in-laws neighbors wouldn’t let me in because I’ve got TB. Why did I get TB?

Sonia encountered this when she went to her in-laws yesterday. With this hurtful occurrence, Sonia did not like this reaction very much. From the way she spoke she was obviously frustrated and let down. Sonia lamented,

It will affect me . If a person says something by mistake [referring to her husband who told his mother], which is not admissible in itself, and you mock at that person and keep on saying, ‘you are married, you are a stupid character.’ If you keep on hearing this, you feel mental depression. You feel low. The same thing is happening here[to me].

This all happened according to Sonia because her husband told her mother-in-law that she has TB. Once they found this out, they asked her not to come to the home until she was cured. Her mother-in-law asked that she stay at her parents’ home for 9 months more. Sonia’s parents went to settle the matter, but with no result, her mother in law was firm with her decision Sonia explains:

So I’d gone for a chest x-ray, they said I’ve got TB and I knew very well my husband would never spend money on me. So, I decided to come to a government hospital. And here they detected it as TB. And now my husband also never spoke anything about this to my mother-in-law, but it was yesterday they opened. The cat was out.

She reported that she felt the
Degradation is not sufficient to giving encouragement to girls. Ok after 9 months I’m cured. After sometime, I’ll get one more disease. A person is not able to help me now and who cannot trust me now will not be able to help me and trust me later on? In life?

Sonia concludes she will stay with her parents and not go back to her in-laws house. For one month, she has been living with her natal mother. Until her husband accidentally told his mother yesterday, Sonia’s in-laws did not know. That has changed and now has a heavy stigma from her in-laws. To add insult to injury, since her husband found out she has TB, he has not come to visit her nor has he spoken to her with in the last month. If she calls him, he will not answer the phone, only hang it up. Sonia predicts that he will not be coming to visit her any time soon.

When I tried to call him up, or try to contact him and say something, he just disconnected the phone or mobile. I never knew my husband would let me down do badly. When he’s my better half and he betrays me. Naturally, no one will heal me.

Sonia decided to come to this clinic because though she asked her husband to see a doctor, he would not take her. So, she made the bold decision to come herself because when she told him, he did nothing. Sonia sat contemplating for a while and explained an emotional upheaval taking place. Sonia laments:

They are telling me ‘first only, you had all these disease. That is why you got her married to us.’ I say no I did not have all these disease. It was only after marriage I got the disease. They themselves have started saying ‘I am seeking for divorce and legal separation’ and all that. That mother-in-law told me TB news. ‘This TB news is a source for divorce and legal separation.’ I haven’t spoken anything about It.!

Not even my parents. My mother in law is saying I want a divorce, not me! How much I think I don’t have any sympathy or consideration for that man!

Before marriage, she was told by her in-law family that she would be ‘taken care of’. If Sonia goes to visit, “they will keep mocking at me”. The mocking has increased to a level where she does no want to go to her in-laws anymore and has in effect been rejected by her husband. Startled at this interpretation of being taken care of, Sonia stated

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10 See Appendix,iv,Figure A
I don’t have sleep in the night sometimes. I cannot tell my parents and I cannot tell my in-laws. I’m just all alone.

Sonia has suffered the full range of the stigma effect. Not only was moved back to her natal home, her decision to stay married is not even up to her. The only thing in her favor is that she does not have any children, to which she remarked,

I’m damn lucky I don’t have children issues. If we have children then that becomes another problem.

Her family and her in-laws will decide if she is to stay married, or to separate. The separation will be decided by her mother-in-law. If she is separated, the husband’s side will not give the 50,000 Rupees (934 Euro) dowry back. Should she marry again in the future, her parents will likely have to give another dowry. Sonia did not want any trouble and the stigma is still looms overhead with the pending divorce or separation. If Sonia is separated, her in-laws keep the dowry, but Sonia will not be allowed to marry again if separated because she is still technically married. Her husband could marry again with little problem. This is the experience most women have, when they contract TB. Despite treatment being available, and her pending cure, Sonia is in a liminal state. Neither married nor divorced, and between health and illness.
Chapter 6
The Interconnection Between Agency, Power, and Gender

In a country where most women are often denied health care, adequate nutrition, and education right from birth, women also have fewer opportunities for economic independence, self-sufficiency and do not, all times, have the power to negotiate sex (Gupta 2004: 19). Women may be given less priority for health needs and generally have less decision-making power over the use of household resources. They often have less knowledge of TB, especially of its signs and symptoms, than men, related to the higher rate of illiteracy among women than among men worldwide (WHO 2005: 27). We see this exemplified in Sonia. Sonia tried to get healthcare by seeking permission from her husband, which is what women have to do in Indian society. When he did not grant her permission, she sought health care on her own accord. This demonstrates agency. Agency indicates action, and tools used to accomplish something. Sonia utilized her knowledge of the culture to navigate the health system and avoid stigma once she found out she had TB. Thus, she utilized agency and power within the range of her gender role. There was a power dynamic between Sonia and her in-laws. As we take a closer look at what Sonia’s stigma means, this will crystallize. The whole stigma fiasco Sonia is experiences mirrors relationship between the social reproduction of inequalities and the persistence of TB (Farmer 1996: 355).

6.1 Agency

Sonia has shown us how she experienced her symptoms of TB and what choices and constraints she faced in her actions. Sonia has used her agency to seek health care with the goal of getting better by taking the tablets and not telling those that she perceived would stigmatize her. Despite this agency, Sonia experienced the worst effects of stigma. Sonia was careful whom she told, like Kamala and Yamini. We have seen that the medical system is providing care when the families do not. When she did speak up about her health, her
husband refused access to the health care system. The refusal of her husband to grant her permission to seek health care reflects her marginalized gender position.

Sonia’s strategy not to tell too many people also indicated agency. If no one knows, she does not get stigmatized, does not move home, and is not mocked. By staying silent as long as possible, she deflected attention away from her illness and she fulfilled the homemaker role, until she was discovered to have TB. When Sonia’s mother-in-law found out from Sonia’s husband that she had TB, her agency was deflated. Sonia’s silent strategy, which shows individual agency, also served as a protective mechanism. It avoided her being stigmatized and kept her life ordered though her body state was not in order.

Through the state of Sonia’s disordered body and life, Sonia’s in-laws have utilized their agency in the form of the power of societal norms via stigmatization. By stigmatizing Sonia, the in-law family reduces their chances of being stigmatized or contracting TB. This stigmatization strategy works in three ways.

1. Using agency for self-advantage

2. Perceived stigma. Having a family member with TB could cause ‘stigmatization by association’, therefore, the source of stigmatization (Sonia having TB) is moved away to the parents’ house and perceived stigma vanishes.

3. Agency via of social perceptions of TB.

By stigmatizing, the in-law family utilized agency. Sonia utilized agency by trying to circumvent telling her in-laws she had TB and sought health care against her husband’s wishes. Sonia’s family did not wish to be stigmatized as having someone with TB in their family. They removed the ‘problem’ (Sonia) and hence the stigma they could encounter for having a family member with TB.

By understanding the social perception of TB, this helps illustrate this point. The perceptions of how someone gets TB, according to my participants, in the following ways: By talking to someone you get TB, TB is transmitted by dust, you get TB from a dust
allergy. By targeting, someone who actually has the disease and mocking them works to keep the person (Sonia) away and protects the people from their fear of contracting TB. This controlling aspect, maintains order in Indian society. If someone believes they know the answer to how something is contracted, this serves as the an

In many non-Western societies, like India, local knowledge systems may perform the same function at a more localized level (Parker, Aggleton et. all 2002: 9). The local knowledge system is of course, is up to the individual who interprets it. In general, as we see with Kamala, Yamini and Sonia, are all too aware of what they suffer from stigmatization if their in-laws or someone else finds out they have TB. Kamala and Yamini have, for the time being, escaped stigmatization by staying silent infront of the right people, but still take preventative measures to avoid the effects of stigma.

Sonia seemed to have the power of agency, but this was eclipsed by the parents. Power was manipulated by Sonia, the medical setting, and the in-law family. This is seen when Sonia decided to seek health care, take medication, and who she told she has TB. The medical setting replicates inequality and society and controls her internally and externally yet provided the care she lacked at her in-laws home. Her in-laws and husband manipulated power by forcing her to move to her natal home, keeping the dowry, and being specifically ambiguous about her return into the family ‘after nine months’. At different times, power was utilized and one group appeared to be in control at different times.

6.2 Power
Medicines carry with them a power, symbolic value - the promise of return to health (Whyte, Van der Geest & Hardon 2001: 29). The pill was power for Sonia; it symbolized her power to get better from her illness and using her own agency to do so. She tried to get better before her in-laws found out and even moved home to avoid any conflict. That is, she was trying to make adjustments to manage her life (Whyte, Van der Geest, & Hardon 2001: 15). By using her own agency, taking tablets keeps the illness from progressing and narrows the space between illness and health. If a person is ill they take tablets when a person is well, they do not have to take tables. For Sonia, taking tablets is directly related to being cured from Tuberculosis. Whereas medical professionals speak of controlling or managing a disease with medication, the users of medicines are usually trying to control not just their physiological symptoms but also their situation (Whyte, Van der Geest & Hardon 2001: 15). As we have seen, this is true for Sonia. Before Sonia took tablets, she was not (presumably) well treated and not stigmatized by her neighbors, in-laws, or husband. Sonia was trying to control the situation by not getting any worse or encountering any consequences for having TB.

In most settings where TB is prevalent, the degree to which patients are able to comply is significantly limited by forces quite beyond their control (Farmer 1996, 351). If as Foucault (1976) maintains, “Wherever there is power, there is resistance” it would seem that wherever there is resistance to power systems, the ‘resister’ is pushed back into the existing framework (Hirschmann 1998: 362). In Sonia’s case (the ‘resister’), she certainly tried to escape this power dynamic by getting permission treatment for her ailment only to be caught in the structure of the medical system and moved out of her in-laws home for 9 months. Sonia made the choice that anyone who has suffered the debilitating symptoms of TB would do; Sonia went to see a doctor. In the context of India, Sonia ‘resisted’ the cultural norm by ‘disobeying’ her husbands wish not to seek health care for a fever she had for over a week.

6.3 Gender
Sonia shows us the relationship between individual agency and structural violence. Sonia is not receiving enough care from the joint family. Getting the fever for a week marked the boundary between illness and health. Sonia ‘disobeying’ her husband, being diagnosed with TB, and getting medical treatment marked the boundary between stigmatized and unstigmatized. Sonia being ill to her in-laws caused them to stigmatize her and force her to move to her parents’ house, which replicates the social inequalities in her society in regards to gender. This brings up power relations in gender, further external control, a doctor is usually male, male family members such as husband uncle or father in law allow or disallow health care and act as gate keepers to health care system. Sonia stated,

Sonia:If my husband was affected by TB he would go visit a private doctor. [Allison: do men get healthcare easier than women?] Sonia: men get immediate treatment, but for females it is delayed [Allison: why?] Sonia: I have to get permission from the mother-in-law, the father-in-law, the husband, and all.

Culture is the result of what people need, more precisely, what people think they need or think they should do because it is socially accepted (Whyte, Van der Geest, Hardon 2002: 137). Additionally, the TB program has power over the patient. The program is externally controlling: controlling days, time, and duration of time to come to treatment. The program is not culturally adapted, gender sensitive, and does not account for the socioeconomic factors other than being free treatment. Therefore, the patient is externally controlled by time and space. The pill given by the medical staff and observation is another form of power. The observer has the power the taker is observed. DOTS, is Directly Observed Treatment, Short Course. Foucault (1980) states “The ambiguous role of medicines as a means of both (self-) control and being controlled is a consequence of the fact that power is not a possession of particular social groups, like doctors, but that it is relational and dispersed (Whyte, Van der Geest & Hardon 2001:61). We saw that throughout Sonia’s story, though she utilized agency, power shifted between Sonia, the in-laws, the TB program itself and ultimately replicated the structural violence in society. We can see that meaning responses are embedded in culturally specific expectations of the healing process. Efficacy is understood in the context of larger healing process, including initial perceptions.
of symptoms, notions of causation and severity, subsequent treatment actions and expectations of outcome (Whyte, Van der Geest, & Hardon 2001: 31).

6.4 Motivating Factors to Seek Treatment

When women get infected, they are often sent back to their parental home and/or stigmatized, like Sonia experienced and Kamala tried to avoid. We can see that the women have a clear expectation for the DOTS treatment to work. They have sought health care and therefore, “just” providing anti-TB medication is not sufficient to ensure that patients are cured, have access to the medication, and are able to get proper treatment with out heavy social consequences, especially if the adult happens to be a woman. Such worries and tension motivated women like Kamala to complete the treatment as soon as possible so they could go back home and their symptoms disappear. Women utilized the cultural notions of TB such as dust allergy to explain how they got TB. We can also see that up to a point they had symptoms that they could live with. Sonia, for example had symptoms for a month, but wanted to see a doctor before but found her fever that did not abate an urgent matter.

6.4a Yamini’s Story
These days Yamini has not been sleeping well. She grumbled at the fact that wakes up around 1am after going to bed at 10pm, she actually wakes up at Midnight and manages to stay in bed for 4-5 hours. Though she voiced her complaint to the doctor, she did not get any tablets. The doctor said she “had habituated these timings”. Yamini is no stranger to coping with things for a long time as she explains her experience with not feeling well and having TB:

For the past 25 years, I’m having a dry cough. I’m having a dry cough and I kept taking homemade medicines. Later on I went to a cancer hospital and I got it checked came there was a swelling on my neck. (She has extra pulmonary Tuberculosis on the left side of her neck that appears as a big lump below the ear.) I had a lump and when I thought it’d be better if I could go and check it at the hospital. When I’d gone to the cancer hospital it was detected that I’m suffering from TB and now that I have come here I’m taking tablets. I kept neglecting my cough. Feeling that it’s just a dry cough nothing to be worried. And I used to take this home made medicines but nothing worked out.

I asked her what type of homemade medicine she took. Yamini said,

I’ve eaten red sugars and then some roots of the trees and boiled them up and I had a drink of them; [the trees are] pepper, turmeric. That’s it. That was for the throat. It hasn’t reduced. My coughing would reduce then again, after six months it would shoot up.

Yamini’s husband recommended that she visit a doctor. She found out she had TB two months before I spoke with her. When she came to know she had TB, “I had asked the doctors to give me a mercy killing.” I asked her why she would ask for a mercy killing. Yamini said “They told me there are so many people with the disease who haven’t been doing this. Why is it that you are doing like this? So I kept quiet.” She elaborated,

I felt this was a strange sort of disease which could not be curable. In my mind I have a feeling that because I’m with out any children, no body to take care of me. When a person is aged, they have the feeling they should be take care of by the children. Since I have no children, I thought it’s not worth living.

I asked what she thought the problem was for 25 years. Yanini stated,
Since I didn’t have parents, no one told me that I have to go and visit a doctor. I just lived with the cough. No one ever bothered about it and I also never bothered about it. I used to do my own medicines. It didn’t work.

Now that Yamini comes to the clinic regularly, in fifteen to twenty minutes with her husband, she feels “I might be cured 100%”

Yamini mentioned living with symptoms the medical staff identified as symptoms of TB. These symptoms to the women, did not qualify for seeking immediate health care. This points to their decision making process. They are symbolically representing the social and symbolic structure of their culture and how it views TB and how it is reflected on them the individual in a negative way through stigma which represents the social control over the woman’s body through culture. The women are controlled by cultural perceptions of what a women ‘should be’ and what a ‘women wit TB’ is. These constructions marginalize and stigmatize women at an individual and cultural level. Women to try to circumvent this stigma through symbolic actions such as remaining silent to avoid stigma, and controlling nutrition, and ignoring symptoms that do not fit their illness model.

These symptoms before medical diagnosis of TB did fit into Yamini’s functional health definition, they recognized they had some symptoms, but did not view their symptoms it as abnormal per se, for a certain amount of time. The women accept a certain level physical discomfort in their life. Only when it is for an extended period time, sometimes up to 25 years, only does the process of labeling ones self as ill take place (Helman 2001: 85). However, it is important to note that all women viewed their symptoms severe enough to seek a doctor.

Illness causations for TB, according to the women occur: within individual, not taking good food, lack of sleep loss of weight, lack of food and nutrition. The disease can also be caused in the natural world resulting from air pollution, dust, and dust allergy, instant cough. One respondent mentioned the supernatural world and said it was from a curse but “could not talk about it”. In the social world women are stigmatized for having TB. Public
knowledge of the sick role opens avenues of support and entitlement, allows for the negotiation of social and household responsibilities (Nichter & Vuckovic 1994: 339). In the case of TB, women avoid public knowledge of their disease and remain silent, quietly fulfilling their household responsibilities.

By taking the medicine, patients acknowledge to themselves and those around them they are truly ill (Nichter & Vuckovic 1994: 339). In DOTS, the observation of patients taking the medication can infer that the patient otherwise would not take the medication, thereby not acknowledging they are ill – represented by the health care providers perception that they would otherwise not take the tablets. This has further power relation dynamics. A patient of course can refuse to acknowledge the sick role by not coming, but the possibility of a health visitor could still force a person into a socially defined sick role, though the person might not be willing to accept the role of being sick. The women acknowledge they are sick and adhere to DOTS, because DOTS legitimates their sick role, but they do not tell anyone else they are sick.
Chapter 7

‘Not Keeping Well’: The Women’s Perspective on Illness

7.1 The Body

Critical to the interpretation of this work is the body politic. It is necessary to gain an understanding of the different bodies and how they relate to the women’s perspective. These ‘three bodies’ are the individual body, the social body, and the body politic (Schepper-Hughes & Lock 1987: 348). The individual body is the lived experience of the body –self. The components of an individual’s body such as mind, matter, psyche, soul, self, and how they are related to each other in health illness and disease are highly variable (Schepper-Hughes & Lock 1987: 348). The social body refers to the body as a natural symbol of a way to think about nature, society, and culture as Mary Douglas (1970) suggested (Schepper-Hughes & Lock 1987: 348). The body in health offers an organic model of wholeness while the body in sickness and other forms offers a model of social disharmony, conflict, and disintegration. The third is the body politic. This refers to regulation, surveillance, and control of bodies - whether individual or collective - in reproduction and sexuality, work and leisure, and sickness and other forms of deviance and human difference, which relies on its ability to regulate populations (social body) and discipline (Schepper-Hughes & Lock 1987:348). By keeping these views in mind, we can better understand the woman’s view of her body.

I asked women about the body in health, illness, and disease. I used a body mapping exercise. I asked questions about health, illness, and disease. They were asked to answer based on what they know. Having a disease is very similar to having an illness, in the women’s point of view. There was not much linguistic differentiation by the women for disease and illness. I realized that I distinguish between illness and disease, and the women have lumped ‘not keeping well’ as the state of the body that is not in health, which for them is illness or disease. Whereas I was looking for a division between categories, I myself made divisions between
To understand how women conceptualize their body I will highlight some of the most representative answers to the questions of,

1. What happens if a person is healthy?
2. Where does someone go if they are ill?

There have been anthropological suggestions to looking at the way illness is interpreted. Namely, Kleinman (1980) has suggested a useful way of looking at the process by which illness is patterned, interpreted, and treated. This is called an *Explanatory Model*. Kleinman defined this as ‘the notions about an episode of sickness and its treatment that are employed by all those in the clinical process’ (Helman 2001:85). Lay-explanatory models tend to be “idiosyncratic and changeable, and to be heavily influenced by both personality and cultural factors. They are partly conscious and partly outside of awareness, and are characterized by vagueness, multiplicity of meanings, frequent changes, and lack of sharp boundaries between ideas and experiences (Helman 2001:85).” Explanatory models are supposed to be used by individuals to explain particular illness episodes and not identical to the general beliefs about illness that are held by that society (Helman 2001:85). The explanatory model does not fit with my study. Though women explained, how they identify if someone is healthy or ill, I disagree with the total definition of explanatory models. I argue that the women convey the general beliefs about illness in their society and are not idiosyncratic. The only thing idiosyncratic aspect is society’s view on Tuberculosis. I find their answers regarding illness and health to be reflections of the society and their culture they live in. The main purpose of the body mapping was to obtain the view of health and illness to juxtapose the response to TB. In addition, women were very clear with their answers, did not change their answers. Moreover, I found them to be fully aware of their ideas and experiences and answered very similarly.
When I asked the question ‘what happens if a person is healthy?’ I received strikingly similar results by five women. One woman responded:

If a person is healthy, his family is healthy, his children are healthy, and even the community is healthy, the society is healthy so one needs to be healthy.

This answer reflects the similar answer where five women mentioned happiness as a part of being healthy and extended it to the larger society. Another women said,

If the person has no piece of mind, he is ill health. But if a person has peace of mind, he is healthy.

The women answered not only about the individual, but indicated a condition worthy of being defined not healthy. One woman attributed a supernatural response by stating,

It is a gift given by god for health.

Finally, one woman stated,

They’ll be looking fine. And moreover, they’ll be very active and normally they stay healthy because of healthy food and healthy habits.

The women’s definition of health were very similar to the WHO definition of Health (1946), which is defined as ‘Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.’ Moreover, if a person is healthy, there is order and balance of the whole community, family, friends, and the person. Health is also substantiated by food. The absence of health or food offsets a woman’s activities.
**7.1b Illness**

Illness is the experience of a health problem by the patient, or lay person (Hardon et al 2001:12). Most women mentioned going to a doctor and taking medicine to get better

> If a person is ill, we’ll ask him to go see a doctor. Or that he can take care by the regular medication.

Being ill results in the body changing from one state to another. An individual loosing weight if they are very ill, and other physical symptoms like a fever and cough marks this. Being ill results in depression which the women termed ‘mental depression’ or ‘a down feeling’,

> [If a] person is ill, they tend to be depressed, and he feels that he’s got no use being alive.

Only one woman mentions isolation

> If a person is ill, they should be isolated from everybody. Loss of weight if he’s very ill.

This causes a disruption of health and necessitates a doctor to intervene and restore the body to the prior healthy state. A doctor is consulted and regular medication must be taken (internally) to restore the healthy state in the body. The medication has a double function, the medication taken internally by the individual also restores the inside and outside of the body visible to the rest of the world. The doctor is the regulator between body stages of health and illness and restores the body to health from illness. The medication is the active ingredient in restoring the body to a state of health.
The women also identified how they know someone is ill. This shows what the women view as abnormal changes and leads them to identify someone who is ‘not keeping well’ the way all women refer to illness in this study. I have included three individual answers.

- I make out if my friend is not keeping well because the way he talks is feeble.

- The body loss of weight and his body language says he is not keeping well.

- When the person talks he feels feeble and weak, loss of weight. By seeing, this we can make out a person is not well.

These comments were nearly all identical responses from all twelve of the women. They recognize a person is not well and provides the person with a functional definition of illness which is ‘not keeping well’. The functional definition of health depends on what is defined by a person as health and illness. It depends on what they consider worth reporting to a doctor and how long they can tolerate the symptoms. If a person is no longer able to function normally (i.e. work), then there is illness. This functional definition of health is common among poorer people (Helman 2001: 84). This is likely based on their need to keep working in daily life to ensure ends meet in a day. The poor are more likely to fall sick and then be denied access to health care and are also more likely to suffer the effects of structural violence (Farmer 2003: 138). This disruption of health necessitates a doctor to restore the body to the prior healthy state so a person can complete daily work and return to healthy status. Medication has a double function, the medication taken internally by the individual also restores the inside and outside of the body visible to the rest of the world. The doctor is the regulator between body stages of health and illness.
7.2 Women’s Health Care Choice

In response to my question ‘where does someone go if they are ill’ eight women responded that someone has to see a doctor if they are ill, of which two divided it into government and private doctors and stated:

   Government doctor. Those who are economically fine will go to a private doctor. If they are economically backward, they will visit a government doctor.

The second woman stated:

   At first, they will visit a private doctor who is close to the house and after they will go to the government doctor.

I even asked the health visitor to weigh in on this issue of which kind of doctor he will go and where the patients prefer to go. He responded:

   Ok. If myself itself if I got any like headache, mild infection like fever, headache, like that I’ll go to the private practitioners. Because in government, they’ll give a Paracetamol tablet in government hospitals, that’s it. They’ll not do. See, according to the service they’ll go to the doctors. It depends on the economical background. See if it is economically good, they’ll go to the private practitioners themselves or private hospitals. So one who hasn’t got the money, they’ll come to government hospitals.

When I asked the women “where do you go if you feel ill”, they all answered “a doctor”. Like the health visitor, women prefer the private practitioner and to spend money on quality drugs when they know they could get the drugs free. Decision for health care from a government hospital was based on three criteria:

   1. Motivation to get better
   2. Stigma avoidance,
   3. Economic position.
Stein (1990) has noted that (pharmaceutical) products, which are supposed to alleviate human suffering, are surrounded by a ‘money taboo’ where healing and earning are kept as separate as much as possible (Whyte, van der Geest & Hardon 2001: 139). Indians do not separate this. Health for them has a cultural and economic meaning (Whyte, Van der Geest & Hardon 2001:137). Medication often serves as a marker of illness severity (Nichter & Vuckovic 1994:339). The women I spoke to realize they were seriously ill and pointed this out by reintegrating the duration of the DOTS treatment was six months.

Medications signify illness identities and an individual can come to be defined by the medicines they consume as well as images associated with these. Stereotypes prevail about the type of people who take particular medicine (Nichter & Vuckovic 1994: 339). There is an idiosyncratic view of TB. Whereas, the negative stigma associated with TB is a reflection negative societal view of women and the stigma associated of TB is from a lack of understanding about the disease.

In India, the dominant view of society in regards to TB, as we remember, is caused by a dust allergy, dust, and talking to someone. As we have seen, women choose not to identify themselves as someone with TB or taking TB medication whenever possible. On an individual level, defining oneself as ill can include a number of subjective experiences of the person such as: perceived changes in bodily appearance, such as loss of weight, changes in regular bodily functions; unusual bodily emissions, blood in the urine, sputum, or stools, unpleasant physical symptoms such as pain, headache, abdominal discomfort, fever or shivering. Excessive or unusual emotional states such as anxiety, depression, nightmares, or exaggerated fears, behavior changes in relation to others, such as marital or work disharmony (Helman 2001:84). This last point, though not mentioned as a symptom of TB, is a result which we have seen women experience due to the stigma associated with TB. In addition, it should be noted that the women behavior was changed in relation to others because they were moved away from others or changed their interactions they had with in-law family members, neighbors or husbands.
Women also did not provide idiosyncratic answers and seemed to answer reflecting clear ideas based on experience which reflected their culture. On the individual level, we can see that Kamala, Yamini, and Sonia, did experience the above experiences in relation to identifying they were ill. We saw that they gave clear answers that indicated that they know how to identify illness within themselves. We can see that there is a consensus among the women in what causes health and abnormal symptoms and signs (Helman 2001: 85). The main point here is that when women identify illness and health there is consensus. Their definitions are taken from society and reflected at the individual level.

Foremost we should recount that explanatory models are based on an individual’s experience with an illness. Firstly, though an individual woman may experience TB, she gets the definitions of how TB is caused by the larger culture, as we see referenced by women listing transmission by dust allergy, and dust. Society explains this disease. TB is regarded in Bangalore as abnormal. The cause of the illness in society is not clearly defined, as we see in a varying array of answers and this causes fear. Symptoms do not have a single cause and can originate from a variety of outside sources. The appropriate treatment for the condition is to isolate, stigmatize, and mock women. The consequences are suffered by the individual women, but is a result on a societal explanatory model of what causes TB. Where the individual takes and transmits definitions from society related to health and illness, the society gives and transmits the definition of TB to the individual.
Chapter 8

‘Signs and Symptoms’: The Medical Perspective on Illness

In most cases, health is seen as more than just an absence of unpleasant symptoms. Women notice if there is a problem with their body. They have specific ways of gauging their health and tracking illnesses. Taking medications is a powerful means of both regulating the body and embodying values. (Nichter and Vuckovic 1994: 335) Taking medication involves more than just taking it; it involves the subtle ideas about self, illness causality, responsibility, the meaning of sickness, and the perceptions of entitlement (Nichter and Vuckovic 1994: 335). Taking medicine is symbolic on many levels. Taking medications involves the assumptions about what is normal and desired, links the body to the body politic, symbolism, gender, stigma, and nutrition. Where the women defined health and illness, the medical staff defined disease. This division takes place because the women are not health experts; the medical staff are and define their health problem of TB a disease. In addition, the symptoms of TB are straightforward and no women listed their symptoms to be of a supernatural source. One woman mentioned the disease was a curse, however, she referred to the TB the illness and not separate symptoms. Aside from this, women did not mystify their answers to medical staff, they simply reported signs and symptoms to the doctor and used familiar terms like ‘cough’ ‘loss of weight’ and ‘fever’. There is not a folk name for TB, and it is not considered a folk illness (Helman 2001:86). The common recognizable pattern is gender inequality, lack of knowledge about TB, and structural violence. These have more of a symbolic meaning attached to society and those who suffer from them.
8.1 Medical Staff's Reasons Why Patients Should Seek Health Care

The DOTS staff, by contrast, looked for specific symptoms that could be TB. Medicine, like Western science, generally is based on scientific rationally; which is all assumptions and hypotheses must be capable of being tested and verified under objective, empirical and controlled conditions. (Helman 2001: 79). This is carried out in the form of sputum exams, microscopy, and x-rays. A patient must have the symptoms for two to three weeks such as chest pain, persistent cough, blood in sputum, fever at night, weight loss. Once presents these symptoms, they must take a test. If someone has a ‘sputum positive’ or x-ray positive result, they move from having the symptoms of TB, to being diagnosed with TB. None of these symptoms include psychological or sociological issues.

These emphasize physiological facts, which reflects Kleinman, Eisenberg, and Good (1978) view of the Western doctor’s view of clinical reality which “assumes that biologic concerns are more basic, ‘real’ clinically significant and interesting that psychological and sociocultural issues” (Helman 2001:80) Women viewed their physical symptoms in terms of how long they could be tolerated before they went to a doctor. Women did not wait very long in making a decision to seek health care. They waited no more than two months, and before they were diagnosed, this DOTS dispensary was not their first stop. The medical staff listed physical symptoms in terms reasons to get checked up. The women listed the same symptoms as the medical staff, but instead they spoke of how long they put up with these symptoms. Most women were referred to the hospital by a private doctor or other government institution. Once a woman identifies that she is ill, she will try to get treatment as soon as possible. The delay in diagnosis on the medical side is usually from the doctors in getting treatment for TB. The delay comes from misdiagnosis as Saravanah points out:

Because a private institution doesn’t know because some of the drugs because they’re practicing MMBS, Masters of Medicine Bachelor of Science MMBS. Ok and other one is Aurvyedic Doctors, DMS. Because some of the doctors don’t know about TB also. They’re not diagnosed properly. [AW: ah] most of main reasons some of the doctors doesn’t collect the TB cases they’ll be soft. So, for this reasons, TB will be spreading so soon. [AW: ah]
So, once they get it, they’ll go to government hospitals. No it is not a question of
don’t know, they will diagnose not proper. Some [private practitioners] they’ll
mistake. They’ll mistake by taking on disease to another disease. They’ll not think
of TB, they’ll like cold cough, that thing. They’ll prescribe only for cold cough.
But unfortunately, the cough wont be reduced, so in that case, they’ll refer to them
major hospitals, so they’ll come to know why they are for the sputum examination
or chest x-ray. They’ll find out if they have TB.

The women are no strangers to this type of experience. One women was told she has
asthma, and had to take tablets, but her symptoms did not subside for two years. Only after
coming to this hospital, did she find that she does not have asthma she has TB. Another
women went to two private doctors, one did not help, and one only suspected TB, after
spending 6,000 rupees came to this hospital and it was confirmed she had TB, and now she
takes tablets. As I mentioned before, women wait varying amounts of time. The other
women waited between two months and two years. We can see that somewhere, women
hindered by the structural framework of tuberculosis programs. This could explain why
despite early care seeking, women may have a longer period of delay before diagnosis
(Brundtland 2000). Evidence indicates that despite seeking treatment for symptoms,
women had a longer delay before tuberculosis was diagnosed (Brundtland 2000).

According to Brundtland (2000)

Some possible reasons for this are: They often sought care from a private
practitioner or a less qualified professional, and waited for the treatment to take
effect before going to the hospital. They did not go to the hospitals where TB
treatment was available, because of the distances to be covered and restrictions on
their physical mobility. Fewer women presenting with chest symptoms were
referred for sputum examination by doctors. It took the doctors longer to diagnose
women with tuberculosis than men, perhaps because they did not present with what
is considered ‘typical’ symptoms: prolonged household cough with expectoration.

Though this suggests there is early care seeking, the delay in diagnosis could be related to
the doctors themselves. The stigma attached to having Tuberculosis is more of a
motivating factor to get treatment and cured as fast as possible.
We can see the symptoms of TB did match the woman’s concept of illness, but in some cases, diagnosis was wrong. Women do seek health care and want to get better. One simple explanation is women cannot afford to be ill. In addition, they have little to gain by being sick, as there is not a real sick role developed. A sick role is the socially acceptable role of an ill person (Helman 2001:85). Women tried to avoid being labeled as having TB for as long as possible because TB is not a socially acceptable disease. This is a paradox, on one hand, there is a socially acceptable role of a sick person, and for these women it is socially unacceptable to have TB. Acknowledging they have TB carries a big social risk and stigma. Neighbors are likely to inquire about a person and their health, and with out a creative response explaining how they are not well, are likely to get a stigma from their society.

I asked Saravanah and Mohan, from the DOTS dispensary how a patient describes TB symptoms to them; before they find out, they have Tuberculosis. The medical staff responded:

Saravanah: They’ll tell the signs and symptoms. ‘I have the chest pain for three weeks, I’m cough for three weeks, I have night temperature during evening time for three months and I cant eat, like loss of appetite, I feel hungry but I cant eat’ they’ll tell. Or that they are loosing their weight. So, for these cases we’ll refer to treatment because they show the signs and symptoms of TB. So we’ll get and collect their sputum so then we’ll come to know. If it is positive, directly we’ll start treatment that is CAT 1 sputum positive cases, if it is negative again, we’ll send for a chest x-ray so there if it is negative it might be some other problem then TB. So according to that the doctor will suggest and prescribe treatment.

Mohan: No. They’ll come for symptoms of cough and fever. We should only diagnose them. {Skip} Cough, fever, chest pain, loss of weight, that’s the symptoms of tuberculosis. 
[AW: what do the patients say their symptoms are?] Yeah they’ll come. Come complain with cough and fever, rising of fever in the evening. They won’t feel hungry.
8.2 Biomedical Framework

The medical staff answered from within the biomedical framework, explaining physical symptoms based on abnormalities. Kleinman, Eisenberg, and Good (1978) view of the Western doctor’s view of clinical reality which “assumes that biologic concerns are more basic, ‘real’ clinically significant and interesting than psychological and socio-cultural issues (Helman 2001:80)” This does not reflect the patients psychological state or their social and cultural background (Helman 2001: 81). Fabrega and Silver (1973) point out that the medical perspective assumes that diseases are universal in form, progress and content and that they have a recurring identity (i.e. TB will be the same disease in whatever culture or society it is in) (Helman 2001: 81). Though TB symptoms are the same in a biomedical framework, this perspective fails the patient in the Indian (and many other) context. The DOTS program does not account for or include the context of health or meaning of the disease for the patients around them. The DOTS program is set up in such a way that it focuses on the physical dimensions and not social. DOTS is failing its patients. It provides a six-month course of treatment for free (which is pro-poor), and cures the symptoms and the disease. Though it is good that the patients are cured, the biomedical framework does not reflect any of the patients’ background. What it does not do is address any of the underlying cultural, socio-economic conditions of the patient or address stigma. Two excellent medical staff shine amidst the top-heavy structure of the DOTS program.

Despite the shortcoming of DOTS program, Mohan and Saravanah have managed to work well with in its constraints. They also have managed to work with the TB patients and get them the best care they can with in the set up of DOTS. They do not wear white coats, they are not doctors (doctors in the maternity hospital all wear white coats), and they have excellent knowledge and rapport with their patients.
Chapter 9
Symbolism and the Sacred Cow

Cultural meanings and practices embody interests and are used to enhance social distinctions between individuals, groups, and institutions. Stigmatization creates differences yet also plays a key role in transforming difference based on class, gender, race, ethnicity, or sexuality into social inequality (Parker, Aggleton et. all 2002: 10). The speechlessness of the women that have TB, symbolize their marginalization, poverty, structural violence and promotes the power of the dominant group. Foucault (1980) stated that the ambiguous role of medications a means of both control and being controlled is a consequence of the fact that power is not a possession of particular social groups, like doctors, but that it is relational and dispersed (Whyte, Van der Geest, & Hardon 2002: 61). Bourdieu and Passeron stated the concepts of symbolic violence and hegemony highlight the role of stigmatization in establishing social order and control, and identify stigmatization as part of the social struggle for power. Symbolic violence is a process where words, images, and practices promote the interests of dominant groups (Parker, Aggleton et. all 9:2002). Foucault, Gramsci and Williams took it farther and stated hegemony is achieved through the use of political, social, and cultural forces to promote dominant meanings and values that legitimize unequal social structures (Parker, Aggleton et. all 2002: 9).

The silence around having TB is the symbol of Indian woman in society: be married, but in the home, be invisible, but have children, and do not demand too much or expect much from government policy. Tuberculosis has a lot in common with the women; it is invisible, unless x-rayed or examined under a microscope, yet everywhere but unseen or heard. Women can be viewed much in the same way, unless you take a close look at them or listen to them, they remain invisible and unheard. People wont talk to them because they could potentially catch the disease, so mocking ensues and the person affected with TB will remain silent, and when people find out, usually they are moved to the natal home.
This cultural process at the individual level serves as:

1) Protective mechanism
2) Distancing cognitively and physically
3) Family avoiding stigma

Therefore, silence as protective mechanism against stigma if someone else doesn’t know a woman has TB, then there is little risk of being looked down on, mocked either by neighbors, in-laws, husband, or outsiders, having to live in mothers house, or divorce, separation, or children staying with husband during treatment and woman going to natal home. Medicine is also a symbol of care (Nichter & Vuckovic 1994: 341). Two husbands wanted their wives to get better. Though they did not spend money on medication, the gesture symbolizes care. In Sonia’s case, medicine symbolizes her marginalized position and lack of care for them by their husbands and joint family, yet does not take away her agency of seeking her own health care. Consulting another doctor after being treated is a gesture of care, which Sonia’s mother showed when she suggested that she see another doctor when she was cured at the dispensary.

9.1 Good Food

Poverty underlies the poor health status of most of the Indian population (Edmonds & Medina 2002: 241). Women’s [low] status does not help this situation. Official health records are not comprehensive or up-to-date, and “female health conditions” are not considered health problems, either by health care professionals or women themselves (Edmonds & Medina 2002: 241). This we saw in the woman’s view of their body and how they defined illness when the symptoms became intolerable, like Sonia’s continuous fever lead her to seek treatment. Most diseases go unreported. Just as reproductive health problems fall into the realm of “private and unspoken diseases” (Edmonds & Medina 2002:241), leading to a culture of silence, just like TB and the related stigma, lead the woman to stay silent. Poverty is a major contributing factor to the ill health and malnutrition of women because of traditional values. Even in households that have enough, women are disadvantaged in terms of food consumption because of traditional notions of what food girls must not eat or that women must eat last and poor boys are fed
better than rich girls (Edmonds & Medina 2002: 241). Among major factors identified for high food insecurity were low income, high illiteracy, low agricultural production, illness of an earning member of the household and lack of land ownership for cultivation (WHO 2000: 44). Data on nutritional status of adults, as determined by the Body Mass Index, indicated that about 50 percent of adults suffered from different of chronic-energy deficiency (WHO 2002: 41). The figure below shows the cycle of poverty leading to the deteriorous effects of health.

**Figure 4: Food Cycle**

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Poverty

Environment                 Poor Diet

Infection ← Malnutrition

Immunosupression
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(Chart adapted from http://www.rkmtns.org/RoleOfNutrition2.htm)

We can see that poverty leads both to a poor diet, and an environment that may be substandard. The poor diet, leads to malnutrition, which leads to immunosupression. The substandard environment can contribute and lead to infection that is compromised from immunosupression, which has been compromised by malnutrition, poor diet, and ultimately poverty. These have more of a symbolic meaning attached to society and those who suffer from them.

Most of the population is vegetarian; this is due to the dominant religion of Hinduism. They will consume dairy products, but in fewer cases, meat, especially beef. The cow is a sacred animal in India and can be see freely roaming around in all parts of the country. There is a minimal amount of meat consumed, such as chicken, fish, and lamb but rarely and usually by the lower caste Hindus and Muslims. Animal bi-products such as dairy and eggs (except for Orthodox Hindus) are consumed. A major protein source is lentils.
Though there is meat consumption, beef is rarely consumed due to the dominant religion and the practice of *Ahisna*, which can also be called the **Dharmic Law Reason.** *Ahisna* is the law of non-injury; it is the Hindu’s principal duty in fulfilling religious obligations as defined by Vedic scripture (Maharaj 1997). A second major reason is the Karmic Consequences, aside from the Vedic scripture; there is a concept of Karmic consequences that is pervasive in India, which dictates that all actions have consequences (Maharaj 1997). Therefore, the avoidance of meat is very common in India and the majority of the population that is vegetarian is Hindu.

The women I spoke too all gave importance to their nutrition. The women did not list an underlying religious reason for not eating meat, though it can be implied due to religious beliefs and practices. The majority of food in India is vegetarian, unless it is marked as non-vegetarian. Food is a very important part of Indian culture. It has many social, religious, and symbolic implications, including maintaining health. The women I spoke to believe the wrong diet causes illness and the right diet maintains health\(^{11}\). The right diet is vegetarian and eating three times a day. There was one exception. Sagita is a 24-year-old woman from Bangalore who married recently in January. Infact, she married having TB, her husband knew and was supportive and suggested treatment for her. Sagita and her husband live in their own home, and visit his in-laws often. She can visit, but cannot tell anyone due to fear of loosing family prestige. Samitra eats three times a day, unless she is late for work, then she just eats lunch and dinner. The following example illustrates the power dynamic and symbolic nature of food.

Husband: I confided in my mother that she’s suffering from TB, so my mother said take non-veg\(^{12}\) and all and you’ll get healthy.

[Allison: why did they say take non-veg?]

Sagita: intake of non-veg will give me strength and calcium and I don’t like beef. They’re very particular in me taking beef. I hate consuming beef, but now since I’m forced to do it, I take it and eat now.

[Allison: do you spend extra money on the beef?]

Husband: no I don’t have problems. We don’t spend separately on food. Whatever money we have we manage with it.

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\(^{11}\) See Appendix vi

\(^{12}\) non-vegetarian
Sagita: after consuming tablets my intake of food is more. And I’ve put on weight.
[AW: so, what is good food?]
Sagita: (looks at husband) non-veg. Good food is non-veg.

The food is used to regulate their body to maintain health. Sagita’s in-law family is more accepting of TB than other woman’s families. Sagtita’s family has not made her divorce their son, has not mocked her, and in fact, are involved in her recovery. Even so, the family is showing care and love through food, though in a rather controlling way. This is viewed as a caring gesture through her in-law family by taking an active role in her recovery.

Sagita’s mother in law has suggested that she consumes meat during the treatment of TB. Though Sagita is a vegetarian, and a Hindu, she is suspending this cultural practice of not eating beef in the name of recovery. On the other hand, her mother is symbolizing her power through food. Sagita is in a delicate situation, for restoring her health takes drastic measures, even forbidden ones that the mother in laws has the power to negotiate. Though Sagita lives with her husband, her mother in law is able to maintain order and a presence in the house by externally influencing Sagita to eat beef, though it is also a caring gesture. The mother-in-law and Sagita (through the swaying of her mother-in-law) see the beef as having a curative property to the illness.

Beef is technically forbidden to eat in the Hindu religion. The Hindu pantheon places many forms of plants, birds, and animals equal with humans and deifies them. Animals and birds are thought not only as *Vahanas* (vehicles) on which God rides, but useful as well. Over the centuries, this has brought about a very healthy respect for all forms of life in the Indian psyche. The cow is sacred not only for being a divine vehicle, but because it has an overall utility value (Giridharan, Kumar, & Muthuswami 2000: 2). Since this particular couple is not very much above the poverty line, there is a relaxing of this long-standing cultural norm. In addition, the mother in law is enforcing her view that protein will cure the daughter in law and speed recovery. The beef now becomes a symbol of status in that affording the beef and obtaining are a financial and symbolic way of showing Sagita she is taken care of and that the family has control over her to the extent that they control her diet.
When faced with tuberculosis, the women do not change their eating pattern of three times a day. Two women reported eating less due to side effects of the medication and tuberculosis. Otherwise, the women did not do anything different to increase their nutrition. The doctors advise to ‘eat good food’ the women do not buy anything different to eat, but they maintain at least two regular meals a day, and most eat three, which has not changed since they took the TB medication. One woman said someone gets Tb ‘if they don’t eat good food’ when I inquired what is good food, she responded ‘I take all types of food, I eat only vegetables and Ragi Ball (south Indian dish).

Yamini, who we remember has been ill for 25 years and took home made remedies, explained two ways someone could get TB. The first way she said, “I feel its poverty and malnutrition, because of that we get TB” The second way was because she did not eat meat.

Yamini: normally doctors tell I’m supposed to take meat but I am a vegetarian and, um, I feel maybe because of this I’ve got TB.
[Allison: did you eat meat?]  
Yamini: no I don’t take.
[Allison: is it because you didn’t eat meat that you got TB?]  
Yamini: everyone tells me its what I eat ‘if you would have eaten meat then this would not have attacked you” I have a feeling.
[Allison: did the doctors tell you to take good food? ]  
Yamini: the doctors advised me to have fruits and greens
9.2 DOTS: The Sacred Cow of Medicine

Inadequate ‘adherence’ to effective treatment regimens remains a problem, and only 60 percent of the diagnosed cases are cured (Sahni 2003: 190). Most women pointed to a lack of nutrition as a factor contributing to getting TB, and that one must eat good food to stay healthy. Good food is a way women can regulate and control their health. If they eat a well balanced diet, they can avoid the pitfalls of malnutrition and maintain health. Women were adamant in saying that they ate well and had enough to eat. Though none of them spent any extra money on food, or increased their intake of food during TB. Doctors and medical staff encourage their patients to eat well, which is well intended but misguided. These patients are poverty line and below and though they eat, they may not be eating as well as they could be, say if they had more money. Therefore, a patient may ‘refuse’ if they have no food, similarly, they may be told to sleep in an open room and away from others, but are ‘noncompliant’ if they do not expand and remodel their overcrowded house (Farmer 2003: 151). The term used in India for someone that is ‘noncompliant’ is ‘defaulter’. The problem underlying this ‘defaulting’ is poverty, stigma, and the program structure. Poverty leads to inadequate nutrition and a crowded house and ill health. Stigma directed towards women, results, in some cases, the women forced out of the joint house and stigmatized. The DOTS program structure is hard for poor people to access if they work. Four of the women had other family members in the same house that had TB. Brothers or husbands that had TB and they would start treatment and stop once they felt better.

Amit, 24-year-old women, who is ‘separated’ from her husband, stays with her natal mother. I met Amit on her first day of DOTS. Amit illustrates the engendered structural violence.

My family my sister had [TB] my husband also has partial TB and next me (meaning he took some TB medication) and, um, I’m not aware how this TB is get. And he’s (husband) not taking any medicine. He was taking medicine for a month or so but once he started getting better, he stopped. He has no interest in going to a doctor. My sister has already finished her medication and she’s well on her way. I have a feeling that its only because from my husband I must have caught this disease. My family is below poverty and even my husband’s side also below poverty. So hence, I have to bear the expenses to get food. I’m working in a garment factory.
Amit feels she could have also contracted TB

Because I’ve taken food not at the proper time, dust allergy, sometimes is hereditary also.

She has been taking tablets for one week. She was admitted to the hospital for stomach pain, for which she felt for one month over a two-day period. The private doctors missed diagnosing TB, but gave her an “IV with drips”. She was readmitted because the government doctor discovered she had Extra-Pulmonary TB in her stomach. At the time of the interview, she had recently discharged from a five-day stay in the government hospital four days before our meeting.

Since her husband has found out she has TB, Amit has suffered from the full stigma experience just like Sonia. According to Amit, her husband has abandoned her. The statement given to the family was,

We have no mutual understanding or mutual interest, so ends the marriage.

Something is unequal here. To recap, Amit’s husband has TB while she was married to him. He did not complete his medication, probably because he had to work, and likely transmitted it to Amit, though she could have easily gotten it from her sister if she had frequent contact with her. The husband was not separated, abandoned, or stigmatized for having TB. Since Amit has been diagnosed with TB, she has been abandoned and forced to accept that there is “no mutual understanding or mutual interest”. Amit explains when this all happened.

Two weeks ago. He stopped visiting me because of the TB. Earlier he never visited, I lived with him. Well my [natal] family said well if you’re not interested, leave it. If you are interested in another relationship, you can have it. Everyone in family is aware.
Amit has been stigmatized and abandoned by her husband. This as we have seen has happened with Sonia too. We can see the interplay of food and engendered structural violence. The food power (provided that they can afford food). Women are primarily responsible for cooking and providing nutrition for the family. This is one sphere that she has power and control over, yet again we see the all too familiar structural violence come in to play. Food (not poverty) is blamed, at least partially by Amit, for her contracting TB. The societal structure is replicated here again. Through stigma, she has been separated by her husband, and though clearly a double standard, now she is participating in DOTS.

9.3 ‘Default’ of the Program or ‘Default’ of the Patients?

Indians who are ‘noncompliant’ with the program are called ‘defaulter’s’. A ‘defaulter’ is explained by Saravanah,

The defaulter, old age, elder, and they’re not able to come the reason is they have to go for work. They have to come alternate days. Monday Wednesday Friday for the DOTS but it they come they’ll get delayed to go for jobs for this reasons they’re not able to come over here. So, for such type of patients we have for local DOTS. That is they don’t even come to hospital or DOTS center they take the tablet near the home. They are satisfied and they’re convenient. The places we arrange the tablets. For there patient convenience, we’ll make arrangements. So they can take the tablet, they’ll go for taking the tablet. After taking the tablet, they can go for work.

A lot of faith has been placed in the structure of the DOTS program. Just as many people place a lot of faith that educational interventions will have significant effects on rates of TB in a particular population (Farmer 1996: 353). The same can be said about the DOTS program. Though there are benefits of Direct Observation, as Saravanah points out

The patient will swallow the tablet in front of staff, and before and all they never, we don’t know. Where the patient will take it or not. We don’t know. They will throw the tablet. So, because of that only the program is successful.
We need to listen to the sick and abused and to those most likely to have their rights violated (Farmer 2003: 239). I have established the position of the women in India and the poor. These people want to get treated and they actively seek health care and treatment for TB. We need programs designed to remediate inequalities of access to services that help all humans to lead free and healthy lives (Farmer 2003:239). Since the public in India have not been asked what needs to be changed, we can derive from this study that the structure of DOTS needs to be changed. One thing that could help in starting to fill this tall order, is make the program more ‘user friendly’ to the public. Saravanah who visits the people that cannot come to DOTS explains,

India is very highly populated they have to work for single building so when poor people get TB they have to come. They will not be able to come to the DOTS days. They have to make convenient to poor people they’re already doing but many people who is sometimes emerging cases like going for out of station in 6 months. So, for those cases we are giving tablet to them. Patients in the community, also that will be done. It should be implemented in DOTS. That is the main thing because poor people are not able because in India people are very poor background they should earn daily wages. Wages then go.

DOTS is set up free of cost and set up by the government who provides free health care. This pro-poor strategy is excellent, except for it is not set up to work for the poor. I asked Saravanah if there could be any changes made in the way DOTS is set up. Since he is the one going out into the field, I feel that his answer speaks volumes.

Yeah it can be changed, like, we have to give the tablets to the nearest places convenient to the people and there’s many patients, like in any case, emergencies like anyone from the patients center expired we have to give the tablet to the patients there also. But AS PER DOTS, it is not possible. [Allison: ahh. That you can’t go for emergency cases?]
S: yeah you can’t go there because DOT means that they have to complete then 6 months for treatment. So DOT it is not possible. So I would go to change the DOTS like if any patient suffering from any long way we have to give the tablet for this thing also. So because that they cannot be committed for that so they can have to tablets in his native place.
[AW: if they are severely ill instead of them having to come.]
S: yeah we can give them 2 strips extra to patient dose. They can go to their native place and again they’ll come back so that they give back the strips and will continue the same thing with them so that should be done.
[AW: they return the empty strips]
S: yeh empty strips. That should be don in DOTS so we have to implement it in DOTS like this. That should be done.
[AW: currently its not part of the program? They have to be direct observed.]
S: yeah that should be implemented. See, DOTS centers is all areas around government hospital is there. It is crucial to look at the program implementation in Bangalore. With in the structure, workers cannot perform their job optimally.

Of course, it is easy to demand more resources and it is hard to produce them (Farmer 2003:244). We can see that DOTS does work, but needs to be more accessible and placed in a cultural context. The director of the hospital explains that when she went to the slum population the area was overlooked,

For years that area is overlooked, the poor slums. All the patients who are taking the DOTS are never present. They cannot come early morning. They can’t come in the morning. The house keeping activities, late they come.

Women should not have to ask for a document stating they are cured, be stigmatized, or divorced for having a disease. Men should not have to choose between their health and earning a day’s wage. Women should not have to suffer with symptoms and not tell anyone she lives with. As Paul Farmer (2003) has learned in Haiti, many of the most important variables- initial exposure to infection, transmission to household members, and most of all morality – are all strongly influenced by economic factors. Similarly, in India, the slum population and the poor do not receive the same standard of intervention. If program developers continue to have more faith in the structure of the programs than faith in the people using them, then this cycle will continue.
Chapter 10

Concluding Remarks and Suggestions

I hoped this work provide a clear, well-rounded picture of women with tuberculosis, the health care providers that serve them and their individual experiences with in this context. Through this, we can see that women are receiving sub-standard care for their ailments in society. This is particularly clear when she is faced with having TB. I have tried to show that structural violence is pervasive in all facets of life for the women. We saw how structural violence perpetuates inequalities in gender, though structural violence is called other things like ‘poverty’ ‘lack of resources’ ‘socioeconomic factors’ ‘barriers’ ‘compliance’ and ‘gender’ Indian women in the home are especially vulnerable to infection as family providers of health care for ailing in-laws, husbands, and children with TB (Morankar and Weiss 2003: 149). The main point is the condition of lack of access at the structural level results in negative consequences for all society members. This mirrors the hierarchical structure of Indian society, where Farmer (2003) points out,

The world’s poor are the chief victims of structural violence-- a violence that has thus far defied the analysis of many who seek to understand the nature and distribution of extreme suffering. One answer is that the poor are not only more likely to suffer; they are also less likely to have their suffering noticed. The task, if this silence is to be broken, is to identify the forces conspiring to promote suffering, with the understanding that these are differentially weighted in different settings.

Women in India have to overcome several ‘barriers’ before they can access health care. Women undertake multiple roles in reproduction, production and child care, they may be left with less time to reach diagnostic and curative services than men (WHO 2005:27). Prompt medical care to women infected with TB may be compromised. It may lead one to inappropriately conclude that women delay seeking health care because of the structural constraints. What we did see is women seek care early, and identify ‘not keeping well’ as cause to visit a doctor. The delay in diagnosis such as women having symptoms for two months to two years or more could be related to the doctors themselves. This is linked to the women’s preference of a private doctor, to a government doctor.
Though women could not afford continued health care from a private doctor, their attempt was eclipsed by received an incorrect diagnosis like asthma before being diagnosed with TB.

Women have clearly defined ideas about health and illness which do not fit into the traditional explanatory model. Women had clear ideas about health and illness which showed us how individual women reflected their cultures view of health and illness. Further, their definition of health matched the definition of the WHO. We saw that causes for TB are defined by the society and are blamed on individual, not taking good food, lack of sleep loss of weight, lack of food and nutrition. The disease can also be caused in the natural world resulting from air pollution, dust, and dust allergy, instant cough. In the social world women are stigmatized for having TB because, TB is not a socially acceptable disease.

Just as women identified health and ill health, the medical staff identified illness from within the biomedical framework, explaining physical symptoms of TB based on abnormalities of the body. Kleinman, Eisenberg, and Good (1978) view of the Western doctor’s view of clinical reality which “assumes that biologic concerns are more basic, ‘real’ clinically significant and interesting than psychological and socio-cultural issues (Helman 2001:80)”

Public knowledge of the sick role typically opens avenues of support and entitlement, allows for the negotiation of social and household responsibilities (Nichter & Vuckovic 1994: 339). We have seen that the women are sent to their natal homes. The in-laws suspend their role of providing care and support. The medical system provides a sick role for the women. DOTS medication has provided the caregiving that the women do not get in their homes.

Over all, we saw a silencing of TB. Just as reproductive health problems fall into the realm of “private and unspoken diseases” (Edmonds& Medina 2002:241), leading to a culture of silence. We can say that TB and the related stigma, lead the woman to stay silent. Women avoid public knowledge of their disease and remain silent. Women quietly fulfilling their
household responsibilities and not speaking of their illness does not indicate passiveness. I argue that it indicates the opposite. Silence indicates an assertiveness of the women. In India, women are viewed as inferior and are seen as having only themselves to blame for their predicament. It seldom sees them as victims a form of oppression or of socially prevalent sex biases (Ghansham 2002:7). Women are aware of the prevailing cultural attitudes, know that inequality exists in their society, as they experience it first hand. By maintaining silence, they are working with in the framework of society and using it to avoid stigma.

TB related stigma has become a marker of unpleasant experiences for women in Indian society. Merely having TB is not discreditable in itself because transmission of the disease is an invisible process. Rather who has TB is the discrediting factor. Women bear the double burden of stigma and poverty. Since women and the poor are devalued in Indian society, it is socially acceptable to separate them from the normalized social order. Silence gives the women power and immunity from the stigma. In addition, silence can be attributed to an internalization of prevailing cultural attitudes. I maintain that the women stay silent because they know the cultural attitudes and which to avoid the experience of being stigmatized. Though women over all do not have control over many aspects of their lives, they can control whom they talk to, whom they tell and ensure proper treatment for TB amidst structural violence.

The silencing of TB reflects pervasiveness of structural violence. Structural violence is something that is ‘in the air’ in Indian society. It is all around but it remains silent, because its sufferers are silenced. Structural violence manifests itself as poverty, inequality, gender biases, and barriers. However, the consequences are acutely felt and its sufferers fall on deaf ears. TB, like structural violence, is also ‘in the air’ and is literally an airborne disease. TB is silenced by its sufferers who are already in the grasp of structural violence; silence themselves to escape the consequences of stigma. Society members must fill their lungs silently to avoid upsetting the structurally violent society around them.
We saw that the biomedical view did not reflect the patient’s psychological state or their social and cultural background (Helman 2001: 81). Fabrega and Silver (1973) point out that the medical perspective assumes that diseases are universal in form, progress and content and that they have a recurring identity (i.e. TB will be the same disease in whatever culture or society it is in) (Helman 2001: 81). Though TB symptoms are the same in a biomedical framework, this perspective fails the patient in the Indian context. Therefore, I believe some suggestions are in order.

**Suggestions**

The Working Woman’s forum was everything the women in the clinic were not. Women apart of the forum are NOT organized; empowered, micro lending supported, and trained with a useful skill to help them earn money. The women I spoke to have agency, and are assertive in getting healthcare. Women had to use their agency to survive a difficult situation. Simply becoming organized, does not improve their situation but it does set them up to take a step in the right direction to improve their situation, ten voices are louder than one. The Indian society is not going to change overnight, and structural violence will not disappear tomorrow, but women can use their agency in a positive way to make the society work for them. By taking a bottom up approach, like the Working Woman’s Forum does is an excellent start. More organizations that work like the WWF are needed in Bangalore, and India in general. The argument that there is not enough money sounds, “nothing short of ludicrous when the world contains individuals worth more than $100 billion (Farmer 2003: 245)”

This is but one suggestion that could empower the women. For in India, you have to work with what you have got. With this attitude, there are plenty of women and plenty of resources that could reach them -- if they fell into the right hands. Managing inequality almost never includes higher standards of care for those whose agency has been constrained whether by poverty or prison (Farmer 2003:129) Claims that we live in an era of limited resources fail to mention that these resources happen to be less limited now than ever before in human history (Farmer 2003: 245). Arguing that it is too expensive to set up programs that reach people that need them the most, or government money that doesn’t
make it into the proper hands, continuously implementing top-down structured programs does not facilitate anything for the poor. Further, by accepting ‘the way things are’ serves as a justification for structural violence and continues to propagate an unfair system. A change in attitude and bottom-up programs are needed that reach the poor and the people who suffer the most from poverty, failed programs, and gender.

The DOTS program is failing the people. This happens in three ways; first, it is the structure, the hours of operation, and education. The DOTS program I worked with has excellent staff who are stuck in the confinements of a structure that limits the options of the people it serves and the staff that serve them. The DOTS staff has successfully implemented everything they have been trained to do, and work well with the patients (which is not part of the training). The structure of the DOTS program is a structural constraint for the staff themselves and the patients, for which I have provided substantial cases of structural violence through out this paper. The medical staff know they serve the poor population, yet themselves are caught in the structural flaws of the system.

To counteract the structural flaws of DOTS, to their credit, the program has even provided a health visitor (one per 100,000 population) to go to give tablets to those who did not make it to the DOTS hours (‘defaulters’). Saravanah, the health visitor, works over time and outside of the hours of official DOTS. What the program should consider is alternative opening hours (e.g. in evenings) for healthcare facilities to cater for those with fixed working hours and commitments (WHO 2005:41)

I would like to take this a step further and suggest they provide two shifts for two different health visitors which could be made available during the evening hours, if not to dispense DOTS then to arrive in the case of an emergency (this is currently not allowed under the structure of DOTS). It would also be beneficial to provide at least one health visitor per dispensary, currently one health visitor is working for three dispensaries. In regards to operating hours, based on my observations, very few patients came for treatment after 11am. Most of the patients come in the morning between 9am and 11am. Some come on a lunch break between 12 and 1pm. The clinic is open until 4pm and should remain open for
the occasional patient. The same clinic could open again, (or remain open) at 6pm until
10pm, allowing those patients who cannot make it in the morning to come and get treated.
The clinic hours could mirror the hours of a private practitioner. Based on my
observations, private practitioners open in the morning from 9-1am, reopen from at 2-4
pm, reopen around 6 and close at 9. Of course, not all private practitioners keep the same
hours; the hours could serve as a template for the DOTS program.

Third, the staff should receive training on stigma, gender, and the effect this has on their
patients. A gender sensitive program should be developed which involves whole families
in the treatment of TB at which time the staff counsels the family and tries to directly dispel
the stigma. Educational campaigns in this setting do not work because they do not reach
the people. If the staff are aware of the consequences women and men face, the program
can be changed and adapted. Saravanh and Mohan, though extremely dedicated and
thoroughly trained according to DOTS, lacked the knowledge of what women go through
when faced with TB and how this affects their health seeking behavior. As Farmer (1996)
points out “The study of borders qua borders means, increasingly, the study of social
inequalities. Many political borders serve as semi permeable membranes, often quite open
to diseases and yet closed to the free movement of cures. Thus may inequalities of access
be created or buttressed at borders, even when pathogens cannot be so contained (266).”

Keeping programs that reinforce gender inequalities and structural violence are not a new
story. What India must do, is what India does best, work with ‘what its got’ and go from
there. We can already see this at work with the Working Woman’s Forum. They have
taken the society and culture and made it work for the people. They have brought the
service to the people, not the other way around. If TB programs took this approach, there
is a chance to improve the current structure. There is currently a lack of anthropological
literature on Tuberculosis in Bangalore with a gender focus and I hope that I provided some
insight into the TB problem and more research continues.
Appendix

i. Note 1

ii. Image 1: Traffic Jam

iii. Chart A: Recommended Doses Under RNTCP

iv. Figure A: Stigma Chart

v. Image 2: DOTS Tablets

vi. Figure B: Nutrition Recommendations

vii. Questionnaires
   a. Women
   b. Medical Staff

viii. Works Cited
i) Note 1:
I asked Mohan, Laboratory Technician, if it is usual for a DOTS center to be in a maternity hospital. He replied:

Yeah normal. It can be anywhere. Dispensary. Then local center is there. An NGO will take the responsibility.

Then I asked ‘does the fact that a DOTS center is in a maternity hospital have effects on the maternity patients?’ To which Mohan replied:

No it won’t they won’t cough. The sputum positive cases it will spread but they should keep; they should take care; they should not cough much. They’ll keep the kerchief and they’ll put it when they cough so the droplets wont go and have contact with the other patients.
ii. Image 1: Traffic Jam Commute to DOTS Center
### iii. Chart A: RECOMMENDED DRUG DOSAGES UNDER THE RNTCP

<table>
<thead>
<tr>
<th>Drug</th>
<th>Dose in mg (thrice a week) in adults</th>
<th>Dose in mg per kg body weight (thrice a week) in children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Isoniazid</td>
<td>600</td>
<td>10-15</td>
</tr>
<tr>
<td>Rifampicin</td>
<td>450*</td>
<td>10</td>
</tr>
<tr>
<td>Pyrazinamide</td>
<td>1500</td>
<td>35</td>
</tr>
<tr>
<td>Ethambutol **</td>
<td>1200</td>
<td>30</td>
</tr>
<tr>
<td>Streptomycin</td>
<td>750***</td>
<td>15</td>
</tr>
</tbody>
</table>

NOTE: * Patients weighing > 60 kg are given an additional 150 mg of Rifampicin.  
** Ethambutol is not given to children < 6 years of age.  
*** Patients > 50 years of age or weighing < 30 kg are given 500 mg of Streptomycin  

(Arora and Gupta 2002:25)
iv. Figure A: Stigma Strategies

**Structural Violence**

**STIGMA**

<table>
<thead>
<tr>
<th>Infected With TB</th>
<th>Uninfected With TB</th>
</tr>
</thead>
<tbody>
<tr>
<td>Woman with TB</td>
<td>In-laws/ Neighbor/ Husband know woman has TB</td>
</tr>
<tr>
<td>+ Fear of stigmatization</td>
<td>+ Fear of Contracting TB</td>
</tr>
</tbody>
</table>

**Anti-Stigma Strategy / Silence strategy**

- Avoid stigma
- Do not tell anyone

**Stigmatized**

**Mocking**

- Stigma strategy / Disease Avoidance Strategy
  - *Divorce/Grounds for divorce*
  - *No one will interact with them*

**Move to Natal Home (separate from husband)**

- *Avoid : conflict with in-laws/divorce/separation from children*
- *Avoid perceived isolation*
- *Avoid being looked down on*
v. Image 2: DOTS Medication
vi. Image 3: Nutrition Recommendations
vii. Questionnaire
a. Women

Clinic Questionnaire

- Introduce Interpreter
- Introduce Myself, From Holland
I am a student from Holland and I’m doing a study interviewing women with TB. I am interviewing women with TB and I ask questions about nutrition, TB, who you talk to, and later the body. There are no right or wrong answers and if you do not want to be interviewed, there is no penalty or consequence. Also, if you choose not to answer a question, there is no consequence or penalty. Would it be ok if I interviewed you? Would it be ok if I used a tape recorder?

Once permission obtained, thank you

Demographic Information

What is your name?
What is your age?
Where were you born?
Are you married?
When did you marry? What age?
Was it an arranged marriage?
Before you married, how many people were in your house?
How many people are in your house now?
Do you have children? (If yes)
What are their ages?
Do you work in the home?
Do you do paid work outside of the home?
Does your husband have paid work?
(If yes) what does he do?
Do your children have paid work? (If yes) what do they do?
Do you or your husband have insurance?

Could you please tell me what you do in a day starting from when you wake up to when you go to sleep?
**Nutrition**

Who cooks in your home?
Could you tell me, if you ate something today? (If yes) what did you eat?
Yesterday what did you eat?
How many times a day do you eat food? Does it always happen like that?
You eat ___x times a day, does this change when you take the tablets?
Do you have enough to eat in a day?
Does your family spend extra money on food for you?
How many times a day does your husband, eat?
What do your children eat in a day?
How many times a day do your children eat?

**TB**

What do you do if TB comes?
Tell me, how does someone get TB?
Who gets TB?
Do poor?
Where does someone go if they have TB?
Do you have TB?
Does anyone else in your home have TB? Did they ever?
Could you please tell me how you came to find out you had TB?
Tell me, how did you find TB came to you?
Tell me, who decided you come here?
How did you feel when you found this out?
How long have you been on the tablets?
When do you come to the clinic?
Tell me, do you come regularly?
Does it always happen like that?
Why do you come?
Why do you not come?
Could you tell me of a time you did not come?
Sometimes there are religious holidays, would you come on a religious holiday?

WHO TELL
Did you tell someone you felt ill?
Who did you tell? Yes (who) no (why)
Why didn’t you tell anyone else? Yes (who) no (why)
When TB came, did you tell anyone you have TB?
Did you husband say something? Yes (who) no (why)
Did your husband tell someone? Yes (who) no (why)
Did your family say anything? Yes (who) no (why)
Did your neighbors say something? Yes (who) no (why)
Did your in-laws tell anyone? Yes (who) no (why)
Did you in-laws say something? How did you feel?
Where do you stay now? – How do you feel staying there now?
If you stay with your mother, can you visit your in-laws?
Tell me, does your husband visit? How do you feel about that?
Where do you children stay? How do you feel about that?

Do you need a document from the TB clinic saying you are cured? What if you don’t?
How do you get the document?
If you tell someone you have TB, do you call TB something else?
Tell me what would happen if you stopped coming to DOTS?
What do people think about TB?
What do you think about TB?
Did you see a doctor? Government or private?
When did you see a doctor?
Did you see an auryvedic doctor?
A religious figure?
Why did you go to this doctor?
What makes a good doctor?
Could you please tell me all about going to the clinic?
How long does it take you to get to the doctors?
How long do you have to travel to get here?
How do you get here?
How much does it cost?
Who comes wit you to the clinic?
When is the clinic open?
When are the doctors open?

Medication
Do you have to take tablets?
How do you get the medicine?
Where did you get the medicine?
Is there always medicine available?
On days you don’t come, do you take medicine?
Does medicine cost anything?
Do you take the medicine?
When do you have to take the medicine?
Could you describe how you take the medicine?
Do you take the medicine the way the doctor says?
Do you do something different?
Do you feel anything (effects) when you take the medicine?
What effects?
Anything else you would like to say?
Anything else I should ask?

---End of interview---
Ok, thank you for your answers, very helpful, happy,

Give option to continue to do body mapping interview or set up appointment. Take small break – coffee, tea, sitting not interviewing —
Explain body interview, no right or wrong answers, it is how you feel no right or wrong
answers

BODY
If your friend tells you they do not feel well, how do you know if they are not well?
How do you know if a person is healthy?
What happens if a person is healthy?
How does a person stay healthy?
Where is health located in the body?
What is health?

How do you know if a person is ill?
What happens if a person is ill?
Where does a person go if they are ill?
Where do you go if you feel ill?
Who do you tell if you feel ill?
Who do you tell if you are ill?
Where is illness located?
Where in the body is illness located?
What is illness?
What happens if you are ill?
What do you do if you are ill?
How do you get better?
How do you know if a person is with a disease?
What happens if a person is with a disease?
Where do they go if they have a disease?
Who do they tell if they have a disease?
Where in the body is the disease located?
What is disease?
How do they get better? Anything else you would like to say? Anything else I should ask?
vii. Questionnaire

Medical Staff Questionnaire

- Introduce Interpreter
- Introduce Myself, From Holland
I am a student from Holland and I’m doing a study interviewing women with TB. I am interviewing women with TB and I ask questions about nutrition, TB, who you talk to, and later the body. There are no right or wrong answers and if you do not want to be interviewed, there is no penalty or consequence. Also, if you choose not to answer a question, there is no consequence or penalty. Would it be ok if I interviewed you? Would it be ok if I used a tape recorder? Thank for time, busy schedules!

Demographic

What is your name?
What is your age?
Where are you from?
What is your educational background?
How did you become interested in TB?
What is your title here?
Do you work anywhere else?
How long have you worked here?
Could you please describe to me a typical day at work?
A good day?
A bad day?
How many hours a day do you work?, begin/end?
What are the hours of the clinic?
What are you responsibilities at work?
What is your case load?
How long have you worked with TB patients? With maternity patients?
Why is the DOTS center in a maternity hospital?
Does the fact that the DOTS center is in a maternity hospital have adverse effects on the maternity patients?

Could you please tell me what it is like to work at a government hospital?
In your opinion, does a government hospital differ from a private hospital? How? Patients-pay-house-perceptions-hours

In your opinion, how is a government hospital similar to a private hospital? How? Patients-pay-house-perceptions-hours

How does an urban setting differ from a rural setting? Similar?

PATIENTS

Do patients have trouble accessing the DOTS center? Why, why not

How do patients come to you?
Who refers patients to you?
Who refers patients to your clinic?

Are there more men or women referred?
Are there more men or women cases?

How are patients diagnosed?
What is the detection rate at your clinic?
What kind of patients come here?
What part of the population does your clinic serve?
What do patients think was wrong with them before they found out it was TB?

How do they describe symptoms to you?
Do patients “default”?
Who defaults?
Why do you think they default?
What do you think of defaulting?
Why do patients come?
Why do they not come?

In your opinion, why do women have a higher delay in receiving health care?

Who oversees your program?

Who observes DOTS?
How many people work for DOTS?
Who administers DOTS?
Are there nurses that administer?
Is the ‘DOT’ part followed?

What kind of records are kept here?
For how long?
For how long after the patient is cured?
Do you provide a document stating a patient is cured? Any document?
How do they get the document? Who asks for it?
Men/women?

Why is TB so prevalent in India?

What is the incidence? Prevalence in Bangalore?

POLICY

What do you think of the structure of the DOTS program?
What do you think of the structure of the TB programs?
In your opinion, how well is DOTS working?

What could be changed?
What could be improved?
What is working/?
How well is this center working?

Should there be a gender-sensitive program?
Are there any gender sensitive programs?

Is there always medicine available here?
Was there a time you ran out of medication?

How does the government policy affect the clinic?

How many dispensaries are there in Bangalore?

Anything else you would like to say?
Anything else I should ask?
viii. Works Cited

Arora, V.K, and Dr. Rajnish Gupta  

Bali, Arun P.  

Banerji, Debabar  

Bhatia, Jagdish, C., and John Cleland  
2001 Health-Care Seeking and Expenditure by Young Indian Mothers in the Public and Private Sectors. *Health Policy and Planning*; Vol.16 (1), pp.55–61

Blanc, Leopold, Katherine Floyd, Pierre-Yves Norval & Mario Raviglione  

Byrne, Peter  

Coleman, P. T.  

Devarajan, Shantayanan & Shah, Shekhar  

Edmonds, Christopher & Medina, Sara, Editors  

Ellis, Randall P., Moneer Alam, and Indrani Gupta  
Farmer, Paul
1996 Social Inequalities and Emerging Infectious Diseases. Emerging Infectious Diseases, Vol 2, No4, pp.259-270.

Farmer, Paul

Farmer, Paul

Fox, Wallace

Ghansham, Devaki Monani

Giridharan, N.V, Kumar, Vijay & Muthswamy

Gothi, G.D.

Gupta, Dheeraj, Kshaunish Das, Balamughesh T, Ashutosh N. Aggarwal & Surinder K. Jindal

Helman, Cecil, G.
Hirschmann, Nancy J.
1998 Western Feminism, Eastern Veiling, and the Question of Free Agency.
    Constellations. Vol 5, no3 pp. 345-368

Hardon, Anita, Boonnmmongkon, Pimpawun, Streefland, Pietier, Lim Tan, Michael.
Thavitong Hongvivatana, Sjaak Van der Geest, Anneloes van Staa, Corlien Varkevisser,
Cecelia Acuin, Mushtaque Chowdhury, Abbas Bhuiya, Luechai Sringeryuang, Els van
Dongen, and Trudie Gerrits.
Publishers, Amsterdam.

Jha, Praveen.
Alleviation in India: An Evaluation. Center for Economic Studies and Planning, Jawharlal
Nehru University. New Delhi, September 18, 2003.

Maharaj, Jai.
    Posted by Dr. Jai Maharaj http://www.flex.com/~jai/articles/hinmeat.html. Visited 7
August 2005.

Morankar, S & Weiss, M.G.
2003 Impact of Gender on Illness Experience and Behaviour: Implications for Tuberculosis
Nanda, Meera.
2003b. Prophets Facing Backwards: Postmodern Critiques of Science and Hindu
Nationalism in India. New Brunswick, NJ.: Rutgers University Press, New Delhi:
Permanent Black (in press).

Narayan, Jayaprakash.
2002 Ensuring a Healthy Future. Lok Satta,
    www.loksatta.org

Natarajan, Mangai PhD.
1995 Victimization of Women: A Theoretical Perspective on Dowry Deaths in India.
International Review of Victimology. Oxon, England: ABAcademic Publishers Vol. 3 no4,
pp 297-308.

Nichter, Mark
1994 Illness Semantics and International Health: The Weak Lungs/TB

Nichter, Mark & Vuckovic, Nancy


WHO Report 2002 Global Tuberculosis Control. Gender and Gender Health

WHO
2000 Nutrition Profile of the WHO South-East Asia Region. World Health Organization Region for South East Asia, New Delhi, India pp. 38-44.

www.bangaloreit.com/html/govtinformation/services_censuspapers.html#p2 Census 2001 Results


www.tbcindia.org/Key.asp Tuberculosis Information Website, Government of India.

www.xe.com/ucc. Online Currency Converter. Rates as of 03.08.2005


http://www.umdnj.edu/~ntbweb/history.htm (1996), History of Tuberculosis, NJMS National Tuberculosis Center.

