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Neglected or Non-compliant? Assessing the difficulties of tuberculosis patients in Salvador-BA, Brazil

Erin Slatery
SIT Study Abroad

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Neglected or Non-compliant?

Assessing the difficulties of tuberculosis patients in Salvador-BA, Brazil

Slatery, Erin

Project Advisor: Juliana Leal Ribeiro Cantalino

Academic Advisors: Dr. Andreia Beatriz Santos, Gabriela Ventura

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Abstract

Objective: The aim of this study is to analyze how *Instituto Brasileiro para Investigação da Tuberculose* (IBIT), a philanthropic tuberculosis clinic in Salvador, Brazil, maintains treatment abandonment rates much lower than those of surrounding public clinics. This study also aims to evaluate how professionals conceptualize and address the difficulties faced by patients.

Methods: Interviews were conducted with 8 IBIT professionals and 16 patients in treatment for tuberculosis in the aforementioned institution via semi-structured and structured questionnaires, respectively. Participant observation guided the analysis of relationships between patients and professionals.

Results: Patients found varying aspects of treatment difficult depending on personal circumstances, and chose IBIT for its reputation rather than their perceived notion of its ability to meet their needs. Professionals agreed that drug addiction and alcoholism are the largest barriers patients face to completing treatment, with financial difficulties also mentioned. Most professionals believed the quality of the IBIT team and their relationship with patients contributed to treatment success, and that social services explained their low abandonment rates.

Conclusion: IBIT addresses the structural barriers that most patients face to completing treatment by means of their social assistance programs without community-based, daily, directly-observed treatment. While the social services offered are essential to treating patient, just as important is the humanized relationship and patient-centric attitudes that accompany the provision of these services.

Key Terms: tuberculosis, treatment abandonment, treatment default, structural barriers

Resumo

Objetivo: O objetivo desta pesquisa é analisar como o *Instituto Brasileiro para Investigação da Tuberculose* (IBIT), uma clínica filantrópica em Salvador, Brasil, mantém as taxas do abandono de tratamento muito menores do que as clínicas públicas próximas. Essa pesquisa também tem objetivo de avaliar como os profissionais conceituam e lidam com as dificuldades dos pacientes.

Métodos: Foi conduzida entrevista com 8 profissionais do IBIT e 16 pacientes em tratamento para o tuberculose na referida instituição, através da aplicação de questionários semi-estruturados e estruturado, respectivamente. Observação-participante guiava o análise da relação entre os pacientes e os profissionais.

Resultados: Os pacientes encontraram vários aspectos do tratamento difíceis, dependendo das circunstâncias pessoais, e escolheram o IBIT pela reputação da instituição, ao invés da noção percebida da capacidade da mesma em satisfazer suas necessidades. Profissionais concordaram que a toxicodependência e alcoolismo são as maiores barreiras que os pacientes enfrentam para completar o tratamento, com dificuldades financeiras também mencionadas. A maioria dos profissionais acreditava que a qualidade da equipe IBIT e sua relação com os pacientes contribuíram para o sucesso do tratamento, e que os serviços sociais explicaram as baixas taxas de abandono.

Conclusão: IBIT aborda as barreiras estruturais que a maioria dos pacientes enfrenta para completar o tratamento por meio de seus programas de assistência social, sem, o tratamento diário, por observação direta de base comunitária. Enquanto os serviços sociais oferecidos são essenciais para o tratamento do paciente, tão importante é o relacionamento humanizado que acompanha a prestação destes serviços.

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*“Já sei me cuidar, já sei tomar remédio agora só me resta curar.
Vou contar o que fiz, fui ao IBIT e agora sou feliz.
Não tenho paciência pra medicação, se parar o tratamento não tem solução.
Quero ficar bom, não quero dor no peito, febre, tosse, escarro, não (2x)
La, la, la, la, la (4x)”*

*Now I can take care of myself, now I know how to take medicine and all that is left is to be cured.
I'll tell you what I did, I went to IBIT and now I am happy.
I have no patience for medication, if I stop treatment there is no solution.
I want to be well, I don't want chest pain, fever, cough, sputum, no (2x)
La, la, la, la, la (4x)*

- Excerpt from “Saúde Musical: Tuberculose”, a musical production put on by IBIT's staff for its patients

*“When a patient abandons treatment, I ask the following question: who abandoned whom?
Right? It's us that abandons them.”*

- Simone, nurse at IBIT

Introduction

Brazil's Tuberculosis Policies

When Brazil implemented its tuberculosis (TB) control plan in the 1970s, it was one of the most progressive in the world. The program standardized the provision of free medications for a 6-month period to anyone diagnosed with tuberculosis (Teixeiral & Procópio 2007). In 1994, Brazil reorganized its tuberculosis treatment options through its *Plano Emergencial para Controle da Tuberculose* (Emergency Plan for Tuberculosis Control), which recommended directly observed care through the country's Unified Health System (SUS), alongside increasing budgets for case-finding and diagnostics. These programs had an enormous impact; TB incidence and mortality fell drastically (Teixeiral & Procópio 2007). However, progress stagnated, and despite having a head start on most countries, Brazil remains one of 22 “High Tuberculosis Burden” countries identified by the World Health Organization, which together make up 80% of tuberculosis cases worldwide (WHO 2014). The failure to eliminate TB as a public health threat is largely due to high rates of treatment default rates; patients who are diagnosed and begin treatment, but for one reason or another stop treatment prior to completion. I intentionally use the word “default” instead of “abandonment,” because the term “abandonment” assigns patient blame and relieves the institution of responsibility. However, the term “abandonment” is much more commonly used, especially in Brazilian literature on TB, and both words refer to the same occurrence: an interruption of treatment lasting at least one month.

In Brazil, there is extensive literature on factors associated with treatment default since 2000, although very few studies are conducted in the Northeast and even fewer evaluate the health system's role in preventing default. Research tends to fall into three categories: risk factors for treatment abandonment, evaluation of the DOTS strategy, and recent studies on the effect of increasing the number of drugs taken at once. The first category has concluded that the most relevant risk factors for abandoning treatment are lack of education, being male, and drug or alcohol addiction (Chirinos & Meirelles 2011, Souza *et al.* 2009, Botelho *et al.* 2005). A review of these studies calls for “the development of studies and new models of care that consider, in their focus, a horizontal relationship between professionals and clients, with dialogue and interaction, establishing care that brings the best results for understanding and following treatment”¹(Chirinos & Meirelles 2011). Evaluations of DOTS are split: some studies claim that DOTS is not a protective factor in preventing treatment abandonment (Abreu &

¹ “o desenvolvimento de pesquisas e de novos modelos de cuidado que considere, em seus enfoques, a horizontalidade nas relações entre profissionais e clientes, com diálogo e interação, estabelecendo cuidados que tragam melhores resultados para a compreensão e seguimento do tratamento.”

Figueiredo 2013), and another, conducted in Rio de Janeiro, found that it doubles the cost of treatment for the patient and the health system (Steffen *et al.* 2014). The efficacy of DOTS depends heavily on how the program is implemented. In Carapicuíba, a low-income city with high TB burden, DOTS implementation increased both cure rates and treatment adherence rates (Vieira *et al.* 2011). Finally, studies have investigated a change in policy from the Brazilian Ministry of Health that increased the number of drugs patients took for the first two months of treatment in order to combat drug-resistance. Studies conducted in Vitoria and Goiânia found that drug cocktails produced severe side-effects in 40-80% of patients. However, neither study found that side-effects had any effect on treatment abandonment rates (Ferreira *et al.* 2013, Maciel *et al.* 2010).

Tuberculosis in Salvador

Salvador has the 3rd highest rate of tuberculosis incidence of any city in Brazil, at 81.5 per 100,000 inhabitants and an absolute number of over 2,500 new infections in 2013 (PMS 2013). Salvador's own municipal program for tuberculosis control often sets lofty goals for their TB statistics; a cure rate of at least 85%, 60% of retreatment cases tested via culture for drug-resistance, 80% enrolled in directly observed treatment, and 90% of contacts examined. In practice, Salvador comes nowhere close to these numbers: cure rates of 70%, 40% of retreatment cases tested via culture for drug-resistance, 25% enrolled in directly observed treatment, and 25% of contacts traced (PMCTS 2012). According to a recent study conducted by Abreu and Figueiredo (2013), treatment outcomes boast only a 70% cure rate, while 10% default on treatment, and 15% are later classified as misdiagnosed. The remaining 5% leave the system either by transfer or death. Changes made in diagnostic procedures in 2013 should drastically reduce the 15% misdiagnosis rate, and leaves treatment default the largest challenge still facing TB control in Salvador (Postos 2014). Default is a major problem because it can lead to drug-resistant strains, mortality of the patient, and further spread of the disease. Additionally, patients who have previously defaulted are 5 times as likely to default again as first-time patients (Abreu and Figueiredo 2013), indicating that there exists a high-risk group whose needs are not addressed by current treatment methods. In Salvador, treatment abandonment at similar rates to that of the rest of Brazil with a treatment default rate of 10% (although this figure is higher if cases of misdiagnosis are not included) and a cure rate of 70% (Abreu & Figueiredo 2013). Research again focuses on risk factors for treatment abandonment, which Abreu and Figueiredo (2013) found to be male gender and previous treatment abandonment.

Treatment Default: IBIT as the Exception

Despite the discouraging statistics for the majority of Salvador, within the city there exists a philanthropic clinic, *Instituto Brasileiro para Investigação da Tuberculose* (IBIT), where cure rates hover around 90% and default rates remain under 4% (IBIT 2013). IBIT, birthplace of the José Silveira Foundation, has a long history in its neighborhood of Salvador, and provides care for 10-15% of Salvador's TB patients, depending on the year. It has been providing free care and *acolhimento* services, social support services, to TB patients since 1937, pre-dating the development of any chemotherapeutic TB drugs. Today, the clinic offers free radiological exams, laboratory services, and distribution of medications, as well as distributing *cestas básicas*, and free bread and soup at the clinic (IBIT 2013). In a city where TB abandonment rates are frighteningly high, IBIT is a shining beacon of light, an indicator that, when it comes to treatment default, the problem may lie with the institution, rather than with a population unwilling or unable to complete treatment. If IBIT can keep patients in treatment while the rest of the public sector cannot, perhaps those patients are being neglected.

Study Design

Objectives of Study

Upon stumbling upon IBIT's treatment rates, the obvious question to me was: how does IBIT do it? Why are their treatment abandonment rates so low? Consequently, this study investigates how IBIT addresses barriers patients face to completing treatment, taking into account the professional narratives surrounding tuberculosis treatment default.

Hypothesis

Going in, I expected to find that complementary services that IBIT offers are intended to address structural barriers to care rather than personal choice of the patient to stop treatment. This means that professionals recognize that the struggles patients face to completing treatment are imposed on them by socioeconomic realities, rather than due to a conscious lack of regard for the treatment. IBIT sees treatment abandonment as their responsibility, not the responsibility of the patient. This hypothesis is based off of other successful treatment programs who also base their services on these tenants.

Theoretical Framework

Paul Farmer, founder of the non-governmental organization Partners in Health, is the father of modern discourse on tuberculosis treatment, having led the fight for the inclusion of multi-drug resistant TB in WHO's recommendations for TB control. I draw on his work, and his mentor, Arthur Kleinman, to develop the theoretical framework of my study and my hypothesis. Kleinman explains in his theory of social suffering that "social institutions, such as health-care

bureaucracies, that are developed to respond to suffering can make suffering worse” (Kleinman 2010). This theory is particularly relevant in institutions created to treat TB, as the motivation behind TB treatment is more often than not the contagious nature of disease; institutions are concerned with preventing the spread of disease from the poor to the rich, and thus are not as concerned with the effect of treatment on other aspects of a patient’s mental, social, and physical health. Any treatment facility with high tuberculosis default rates is likely causing more suffering for the patients than it is alleviating.

Farmer elaborates on Kleinman’s theory in with respect to treatment noncompliance narratives, explaining that “willful noncompliance is, often enough, what we term a ‘diagnosis of exclusion,’ essentially barring treatment for those unable to afford it” (Farmer, pg. 165, 2005). He explains that “doctors may instruct their patients to eat well. But the patients will ‘refuse’ if they have no food. They may be told to sleep in an open room and away from others, and here again they will be ‘noncompliant’ if they do not expand and remodel their miserable huts,” (pg. 151). In evaluating factors that lead to treatment default, he says that professional explanations fall into two categories: cognitivist-personalistic and structural. The cognitivist-personalistic pole emphasizes agency of the patients, e.g. claiming that patients abandon treatment because they believe illness is caused by sorcery. The structural pole instead focuses on poverty, explaining that constraints on agency prevent patients from completing treatment. Farmers implores that we focus on the structural pole, and ignore the temptation to blame failure on patient ignorance (pg. 151).

Worldwide, studies have demonstrated that patients previously labeled “non-compliant” by the health system could achieve 90-100% cure rates given the right program. These programs tend to focus on community agents or nurse who provide personalized care to the patients, and provision of food to patients throughout the duration of directly observed chemotherapy, short-course (DOTS, or in some cases DOTS+ to refer to treatment regimens for multidrug-resistant strains). Here, I provide a brief sampling of these from Russia, Haiti, Peru, and Bangladesh; these examples illustrate that factors like alcoholism, drug-resistance, belief in spiritual causes of disease, and even resource-poor treatment facilities are insufficient explanations for treatment abandonment.

The “Sputnik” program implemented in Tomsk Oblast, Russia provided more personal care to a high-risk group of multi-drug resistant TB patients who had previously defaulted on treatment, many of whom had been incarcerated or suffered from alcoholism. The cure rate within this group increased from 50% to over 90% after Sputnik was implemented, where one nurse was assigned to observe 5-7 patients per day in the location of the patient’s choice.

Rather than drawing funds away from easy to treat patients, the program actually helped improve TB infrastructure in the region and prevented further complications caused by drug-resistance (Keshavjee *et al.* 2008). In Haiti, patients were defaulting at high rates despite provision of free medications. Community health agents, who shared the socioeconomic status of the patients, believed those who abandoned treatment were the most economically disadvantaged, and thus the sickest, and that they returned to providing for their families as soon as they felt better. Physicians and nurses believed TB noncompliance was due to a belief in sorcery. To test, this, 50 patients were enrolled in a program that provided financial incentives, food assistance, and nurse visits at home when they failed to show up for treatment. Another 50 patients began the normal free treatment program, without complementary services. While 100% of the patients given complementary services were cured, less than 50% of the patients in the second group completed treatment. Although most patients in both groups believed sorcery played a part in their disease, the researchers found no correlation between this belief and ability to complete treatment (Farmer, 149).

Studies in Lima, Peru and Bangladesh show similar results. Assigning a certain number of cases to a community agent, whose responsibility it is to ensure patients take their medications everyday, and providing food alongside medicine, showed drastic improvements in cure rates. In Peru, researchers concluded that “community-based outpatient treatment of multidrug-resistant tuberculosis can yield high cure rates even in resource-poor settings,” (Mitnick 2003). In a program sponsored by the non-governmental organization, BRAC, in Bangladesh, researchers found that *shasthya shebikas*, female volunteers that are recruited and trained by BRAC to provide a range of essential healthcare services to their communities, were the essential component of a tuberculosis control program (Reichenbach 2011). Regardless of the cultural context, addressing economic barriers to care through community engagement allowed all patients equal access to an efficacious system for tuberculosis treatment. Farmer’s insistence on the structural pole, rather than the cognitivist-personalistic, in barriers to treatment is supported by field research.

Personal Motives for Choosing Topic

At this point, it is worth mentioning that my interest in studying tuberculosis stems from the work of Paul Farmer. I stumbled into my interest in TB completely by accident; my introduction to public health and medicine as a form of social justice came through Farmer’s work. The disease to me is the ultimate metaphor for the pitfalls of global health, and I since reading Farmer’s biography, *Mountains Beyond Mountains*, as a junior in high school, I have dedicated most independent academic research endeavors to various aspects of the disease

(lab research on the bacteria itself, historical investigations of the gendered nature of the disease, policy proposals for the modern United States, mathematical models of the spread of TB in relation to rapid urbanization in Sub-Saharan Africa, and even proposed public health research on TB reinfection of migrants in Shanghai). Imagine my surprise when I found a TB clinic on the route from my homestay to the campus where I attended classes everyday. After an initial meeting with one of IBIT's nurses in September, I knew I had to do my research there. Finally, the significance of my research would not be a list of statistics about worldwide mortality or incidence rates, but a patient sitting in front of me, having overcome incredible barriers to defeat the disease. I have never come into contact with a TB patient prior to my time in Brazil, and it has already increased my interest in the disease just to put a face to the symptoms, the structural barriers to care, and the gratifying success stories. I hope to pursue an MD/MPh, with a focus on the epidemiology of TB in my public health education, and I want to know more about the lived difficulties of both people who dedicate their lives to treating the disease and people undergoing treatment for the disease.

Rationale for Research

While risk factors for treatment abandonment have been evaluated extensively, there is no clear Brazilian literature available on experimental provision of complementary services to address these risk factors. IBIT stands as a potential model for future studies, as it appears to have addressed these factors for their patients in Salvador. I hope to further investigate the relationship between the patient and the professional, as the experiment I mentioned earlier of Farmer's in Haiti, he found that workers with horizontal relationships to patients were more likely to unearth the real reasons they were defaulting on treatment (Farmer, 151). By contributing public information on the structure and function of IBIT, I hope to guide further research into the effectiveness of similar structures implemented in the public system.

Methods

Research Site: Salvador and IBIT

Salvador is the third largest city in Brazil, and also has the third highest rate of TB incidence of any city in Brazil. It is historically a colonial port city, lying on the eastern coast of Brazil on a peninsula between the Atlantic Ocean and the Reconcavo Bay, and has a high percentage Afro-descendant population due to its long history of slavery. The population of Salvador is around 3 million people (IBGE 2014), and the city is divided up into 12 sanitary districts. IBIT lies in the Barra/Rio Vermelho sanitary district, shown by a star in Figure 1.

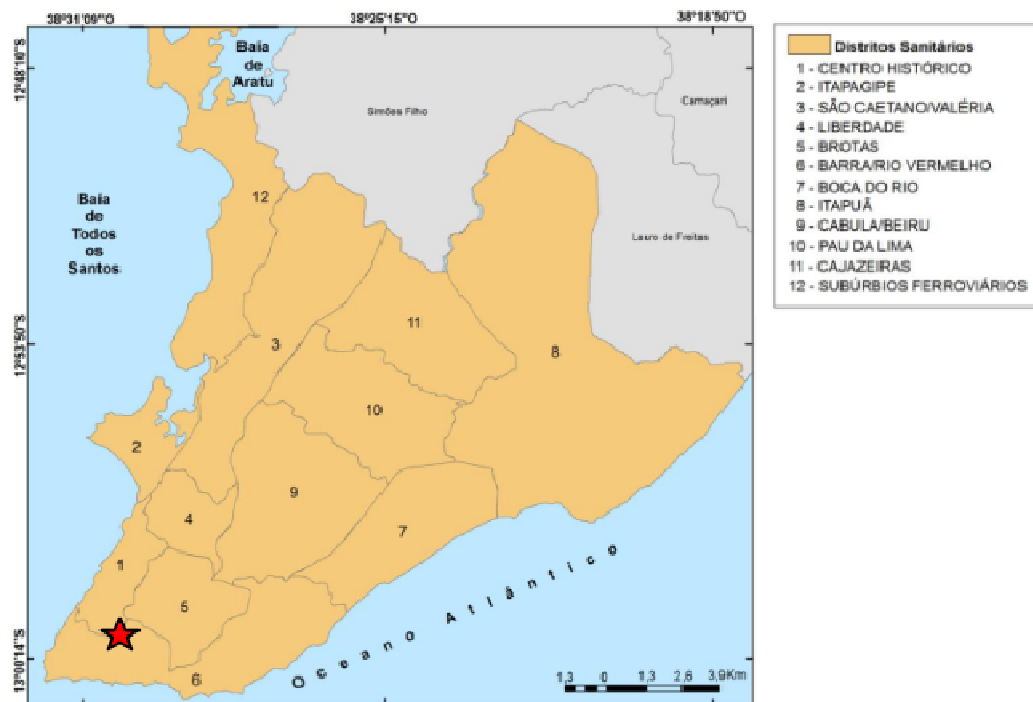


Figure 1. Salvador's Sanitary Districts and the Location of IBIT

SEI, 2008

IBIT serves as the secondary reference center for tuberculosis in this district, and all residents of the Barra/Rio Vermelho district automatically receive treatment here through SUS. However, most of IBIT's patients come from the peripheries of Salvador, specifically São Caetano/Valéria and Subúrbio Ferroviário (Simone 2014). These districts encompass historically socioeconomically disadvantaged populations, and have some of Salvador's highest rates of TB. In fact, combined the two sanitary districts account for at least 23% of Salvador's TB incidence.² The patients from districts outside can receive their treatment from their local, primary health units, but many choose to make the trek to IBIT instead. IBIT sees approximately 300 patients every year.

² Like many statistics presented on TB in Brazil, the statistics for TB incidence by sanitary district in Salvador are unreliable: 15% of cases are reported as "ignored/blank" for sanitary district. It is difficult to say where these "blank" cases occur, but not unreasonable to assume that these two districts account for more than 23% of Salvador's TB.

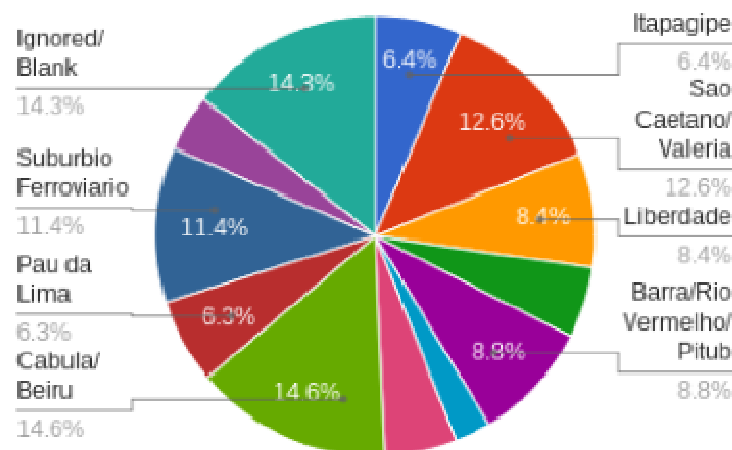


Figure 2. Tuberculosis Incidence by Sanitary District
SINAN 2014

Professional Interviews

The heart of my study was a series of 8 semi-structured, formal interviews with varying professionals at IBIT. In order to alleviate complications due to language, I prepared questions ahead of time with my Portuguese teacher and recorded 6 of the 8 interviews so that I could re-listen to catch any subtleties of language I might have missed. Participants were chosen through a former nurse of 18 years at IBIT who now channels her passion for TB into IBIT's research center after, as she told me, "they won't let me retire!" The nurse, who I will refer to as Maria, is well liked by staff and patients, and stops often while walking through the halls of IBIT to greet people with a smile and cheerful conversation. I interviewed professionals from the three major sections of IBIT that regularly interact with patients; nurses, doctors, and social assistance workers, and made an attempt to interview professionals who had been at IBIT for a varying amounts of time, from 3 months to 55 years. There are other types of professionals who work at IBIT, but few have significant interactions with patients. Within each of these three distinctions, Maria chose the professionals I interviewed by convenience and familiarity.

Collection of Background Information

Only limited information on IBIT is available online, so it was necessary for me to gather background information before beginning my investigation. I gained access to IBIT's extensive statistics on their own indicators again through Maria. This answered some basic statistical questions on IBIT. I collected information on IBIT's treatment structure and history by extending my interviews with relevant professionals. After asking the same personal, opinion-based questions to all professionals, I would follow-up with factual questions relevant to their specialty.

Patient Surveys

I conducted simple surveys in order to determine why patients had chosen IBIT and to assess the major difficulties they faced during treatment. The questionnaire was closed-ended, with an option for “other”, and I derived my list of possible difficulties from a previous study done on social barriers to tuberculosis treatment (Weiss 2008). I used convenience sampling to choose patient, spending 5 full workdays (8:00 AM-4:00PM) waiting in the nurse’s triage office and requesting any patient currently in treatment respond to my questionnaire. My data represents a cross-sectional study that cannot be generalized to the population of IBIT tuberculosis patients, let alone the population of TB patients in Salvador. I was looking for a specific population, though; I limited my surveys to patients who had been in treatment for at least 2 months for active tuberculosis, and disregarded patients undergoing chemoprophylaxis, most of whom were young children. Due to the relatively low education level of many patients and high rates of illiteracy, I read questions aloud and patients indicated what option they wanted to choose. This method of sampling minimized risk to patients, as they were in a room where they were used to discussing their symptoms, and nurses helped me explain my study if my Portuguese proved insufficient. Additionally, the questionnaire did not inconvenience patients because I administered it in the 5 minute while nurses checked them into the online system and arranged their medicine. No patients refused to participate in the study, and in total I was able to survey 16 patients. The average age of participants was 40, with a range of 19 to 67, and the split between sexes was 50% male, 50% female. Patients had been in treatment for an average of 3.4 months, 25% had a serious co-morbidity, and 31% were undergoing retreatment. I collected information on co-morbidities as they can affect the major difficulties that patients face throughout treatment, and I collected information on retreatment because it is usually an indicator of past incomplete treatments and could be used as a proxy variable for looking at patients likely to abandon treatment.

Participant Observation

I conducted participant observation mostly within the nurse’s room, where patients pass through to pick up medication and schedule appointments. Here I observed nurses, and occasionally social assistance workers, interact with patients. I supplemented this with observations in public waiting areas, where I could observe professionals informally interact with patients outside their offices; this was my only opportunity to see doctors interacting with their patients, for example. Finally, I observed a lecture given to a room of about 30 patients on December 4, the municipal day dedicated to the fight against TB.

Limitations and Delimitations

A major limitation to my study was time. I was unable to randomly sample patients or gather enough responses to draw any connections between personal identifiers and responses. I also was not able to determine which patients might or might not default on treatment while collecting data, although I made an attempt to estimate this by asking if patients had previously been diagnosed with tuberculosis. It is likely that most of the patients I spoke with will successfully complete treatment, and the difficulties they list do not put them at risk for abandonment. I still think it is worthwhile to study the difficulties that any patient faces during treatment, as I believe social institutions created to serve should not in any way contribute unnecessarily to further suffering. There was also some bias in filling out patient surveys. Because I administered them verbally, patients would often respond to my question before I had listed the answers, and then I prompted them to fit their answer into one of the categories I had already outlined.

In professional interviews, I had more access to higher-level, long-term professionals, who may have a different opinion than newcomers. I attempted to balance this out with interviews to 2 professionals who had been there 3 and 15 months respectively, but all other participants had worked about IBIT between 7 and 55 years. Participant observation was biased to interactions between nurses and patients, as I had to spend time in the nurses' office to avoid missing any patients coming in to pick up their medicine. Finally, I relied on people who had left the public system, and were therefore more likely to be critical of it, for all information about the public system. I do not see this as a major limitation to my study, as the failings of the public sector were a motivation, but not a formal subject, of my research. The information I collected functions more to help me understand the opinions of the people I interviewed than the state of public clinics.

Ethical Considerations

The largest ethical concern in my study is that I will be studying an at-risk population, patients undergoing treatment for TB who are generally low-income, have low levels of education, and therefore may have trouble giving consent. It can be stressful and uncomfortable for patients to discuss their own TB diagnosis and experience due to stigma associated with the disease, so I limited my interactions with patients to short surveys that were focused on giving feedback on their experience at IBIT rather than asking for personal details. In asking patients to participate in my study, there was some risk of a power dynamic between us, as I was wearing a lab-coat that identified me as an affiliate of IBIT, and nurses directed patients to speak with me while they waited. However, I made sure to clearly explain to all patients that participation in

my study was not mandatory in any way, and that they could refuse to participate if they did not want to. I limited my interviews to professionals who treat patients. With professionals, I risked mostly being a nuisance or interfering with their schedules, but I made an effort to only talk with professionals during their downtime in office. In participant observation, I risked interrupting the comfort and privacy of patients. Due to the large number of IBIT professionals who come in and out of the nurses' office everyday, I do not think I added any additional burden to patients, and I made an effort to smile and direct patients to the nurses if they asked me a question.

Results and Discussion

IBIT's treatment program

IBIT's program is based on a long history of treatment, beginning with Dr. José Silveira and his wife, Dona Ivone Silveira, in 1937 (Rita, 2014). The institution was the birthplace of the José Silveira Foundation, which provides various forms of healthcare services all over Salvador. Today, this philanthropic foundation funds the clinic (Rene, 2014). IBIT treats solely non-drug-resistant TB; all patients with drug-resistant strains or serious co-morbidities, like HIV/AIDS, are treated at Hospital Octávio Mangabeira. Patients with less-serious co-morbidities, like diabetes, continue to receive treatment for these diseases at their home USF (Simone 2014).

IBIT offers all services related to a normal tuberculosis treatment. First, it contains doctors specialized in diagnosis of TB and diagnostic and in house laboratory services for culture, sputum, and X-rays. The clinic then offers free medication and check-exams throughout the course of a patients' treatment, and asks the patient to bring in anyone they live with to also get tested. The clinic administers drug-resistance tests and HIV-tests to all who are diagnosed with TB, and provides chemoprophylaxis for at-risk patients with latent TB, most of whom are children (Simone 2014). In addition to this, IBIT provides bread and soy milk to patients twice a week; in 2012, 60,330 portions of bread and milk were distributed (IBIT 2014). IBIT also provides *cestas básicas* for anyone eligible, which is approximately 10% of patients (IBIT 2014). IBIT also assigns a social worker to each case, who is responsible for calling anyone who fails to show up for their appointment, and goes to visit the patient at home and bring them medicine if they still fail to come to their appointments. In addition to this, patients receive a stipend of R\$24 every month they come for treatment, which can be used for whatever will bring the most security to the patient, but is informally intentioned to cover travel costs to-and-from the clinic. In addition to this, IBIT puts on lectures in their own auditorium, which are open to patients and families of patients, and contributes to health fairs that give lectures in communities (Sheila 2014). IBIT does not seek out patients, as it historically did, but instead relies on government propaganda that instructs patients to seek out treatment for TB if they have a cough for over 3

weeks (Rene 2014).

Professional Perspective: Why do Patients Abandon Treatment?

This question, phrased “Why do you think patients abandon treatment for tuberculosis?” caused some confusion for professionals, who would often begin their response by telling me that none or few of their own patients abandoned treatment. Answers varied slightly depending on whether professionals interpreted this question as why their own patients abandoned treatment or why patients in the public sector abandoned treatment. For example, the explanation “organizational failure,” meaning that the institution providing care lost track of the patient, applies mostly to the public sector, not IBIT. However, I chose to display all answers together. Results cannot be interpreted as the result of a checklist where I asked each professional to tell me whether or not each factor contributes to abandonment; most professionals told me that many factors contribute to abandonment and would likely agree that all factors listed contribute. However, it is still relevant to look at the frequency with which different factors were actually mentioned.

The results of this question are demonstrated in Table 1 and Figure 3, below. It is difficult to group these explanations into a cognitivist-personalistic pole and structuralist pole, although the vast majority fall into the structuralist pole. For example, 6 out of 8 professionals mentioned financial difficulties, which they attributed to travel to the clinic for patients who lived in the interior of Bahia or the provision of proper nutrition to prevent severe side-effects. This is clearly a structuralist answer. Homelessness, organizational failures on part of the health systems providing treatment, and lack of family support also clearly fall into the structuralist pole. Each one of these explanations came up a few times, and are interrelated. More common were two explanations that are difficult to categorize: addiction, and the phenomenon of the disappearance of TB symptoms a couple weeks into treatment.

Profession	Drug Addiction	Alcoholism	Financial (includes travel)	Misinformation	Feel Better	Organizational Failure	Lack of Family Support	Homelessness
Nurses (3)	x x x	x x x	x x	x x	x	x	x	x x
Doctor (3)	x x x	x x	x x		x x		x	
Social Assistance (2)	x x	x x	x x	x		x	x	

Table 1. Professional explanations for why patients abandon treatment

This table groups responses by profession. 3 participants are nurses, 3 are doctors, and 2 work in social assistance. An “x” represents a mention of a specific factor as a reason for treatment abandonment during a semi-structured interview.

Every professional told me that drug-addiction causes abandonment, and most grouped alcoholism and drug-addiction together. Subtleties of language, however, split answers into

either a cognitivist-personalistic pole or a structuralist pole. Some described it more as a structural problem. One nurse told me that crack has invaded Salvador; because it is so cheap, it is accessible and causes people to lose familial support. She said that drug-addiction and alcoholism “Are the biggest villains that confront us during treatment.” This answer- that addiction itself is the issue- is a structuralist answer. However, other professionals told me that drug-addicts and alcoholics often abandon treatment. This is not actually an answer to my question, as it tells me *who* abandons treatment instead of *why*. Another nurse explained to me that drug-addicts had low self-esteem, and little interest in treatment to begin with- this seems more like a cognitivist-personalistic response. Other professionals’ answers did not even fit clearly into one of these two categories, which is why I categorized these responses into one column. I want to emphasize that professionals who framed drug-addiction either way likely care equally about their patients. However, seeing addiction as the enemy and seeing drug-addicts and alcoholics as difficult patients can lead to different approaches to the same problem.

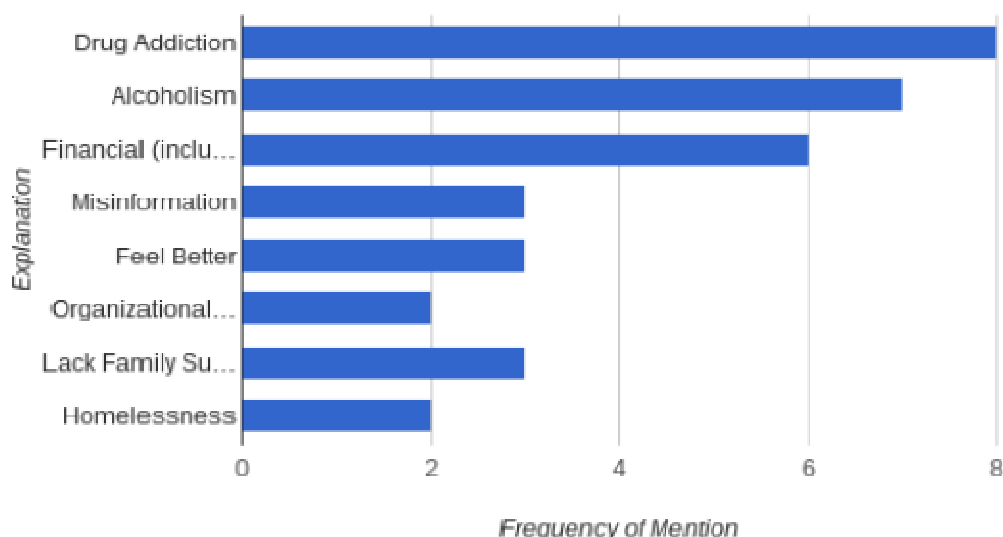


Figure 3. Professional Explanations of Treatment Default

Many professionals also explained to me that patients feel better a couple weeks into treatment, and this can lead to treatment default. However, 3 professionals framed this in terms of lack of information; patients only default when they feel better if they are confused and do not understand that they have to continue treatment (labeled as “misinformation” in Table 1 and Figure 3). One of the social assistance workers told me that patients sometimes are confused when they get a “negative” result on their sputum test 3 months into treatment, and believe that they are cured, and she has to make sure they understand the importance of completing treatment. A lack of information about treatment is a structural explanation for treatment default.

However, another 3 professionals described patients as wanting to stop treatment as soon as they felt better, and seeing it as their role to motivate patients to continue. This falls more under cognitivist-personalistic pole; it blames the attitude of the patient for failure to comply. Regardless of their explanation- lack of information or lack of commitment- all professionals still saw it as their own responsibility to prevent patients from giving in to the misguided temptation of stopping early. One doctor told me he understood it: he thinks if he were in treatment, he would want to abandon, or as he put it “Give me medicine for 5 days, and I will abandon after 3.” The much more dangerous explanation is one I found in a Brazilian news article, which incidentally quotes a nurse working a secondary reference center for tuberculosis in the public sector:

“The biggest problem in recuperation is the lack of commitment from the patients, who stop using the medicine because they feel some improvement. ‘This attitude causes the disease to be stronger and more resistant to medication, and sometimes the treatment will last longer than estimated’”³

Professionals at IBIT may believe that patients want to stop treatment as soon as they feel better, but they frame this as their own responsibility to prevent. To say that a lack of commitment, a bad attitude, of the patient directly causes abandonment disregards the role of the institution in. It is not be a bad thing that patients are not forced to suffer through the exhausting symptoms of TB for the full 6 months of treatment.

Also interesting in these responses was the complete lack of mention of the contribution stigma or severe side-effects to drugs to default. Both of these factors came up later in the discussion of patients’ major complaints. Although side-effects are a major concern for patients, past studies have also shown that they do not affect whether or not a patient completes treatment (Ferreira *et al.* 2013, Maciel *et al.* 2010). Stigma has similarly never been shown to affect treatment abandonment, but is another major difficulty patients face during treatment according to these same professionals. That neither of these difficulties are seen to affect abandonment speak to professionals’ confidence in the resolve of their patients.

³ “O grande problema na recuperação é a falta de comprometimento dos pacientes, que param o uso dos medicamentos por conta própria ao sentir alguma melhora. “Essa atitude faz com que a doença fique mais forte e resistente a medicação, e por vezes o tratamento pode durar mais que o tempo estimado”

Difficulties with Treatment

Professional Response

Profession	Stigma	Confusion	Side-Effects	Financial Difficulties	Time/Inconvenience
Nurses (3)	x x	x x	x x	x	
Doctors (3)			x x x	x	x
Social Assistance (2)	x	x		x x	x

Table 2. Professional response to major difficulties faced by patients

This table groups responses by profession; 3 participants are nurses, 3 are doctors, and 2 work in social assistance. An "x" represents a mention of a specific factor as a reason for treatment abandonment during a semi-structured interview.

Unlike abandonment explanations, the professional response to the difficulties faced by patients during treatment varied significantly based on the profession of the participant. Results can be seen below in Table 2 and Figure 4. This makes sense; a doctor should hear more about the side-effects to the drugs they describe, and social assistance workers are more likely to hear about everything but side-effects. Nurses, on the other hand, seem to be the catch-all for complaints; they reported a large variation in patient complaints and difficulties. The most commonly reported difficulty was side-effects of the powerful chemotherapeutic drugs. This is followed by confusion as to how they were supposed to administer treatment or prevent transmission, and financial difficulties faced by patients. Financial difficulties mostly referred to patients in the interior, who have trouble paying for lengthier transportation costs. Interestingly, professionals generally did not report that patients from the interior complained about the inconvenience of coming all the way to Salvador for treatment, only its financial cost.

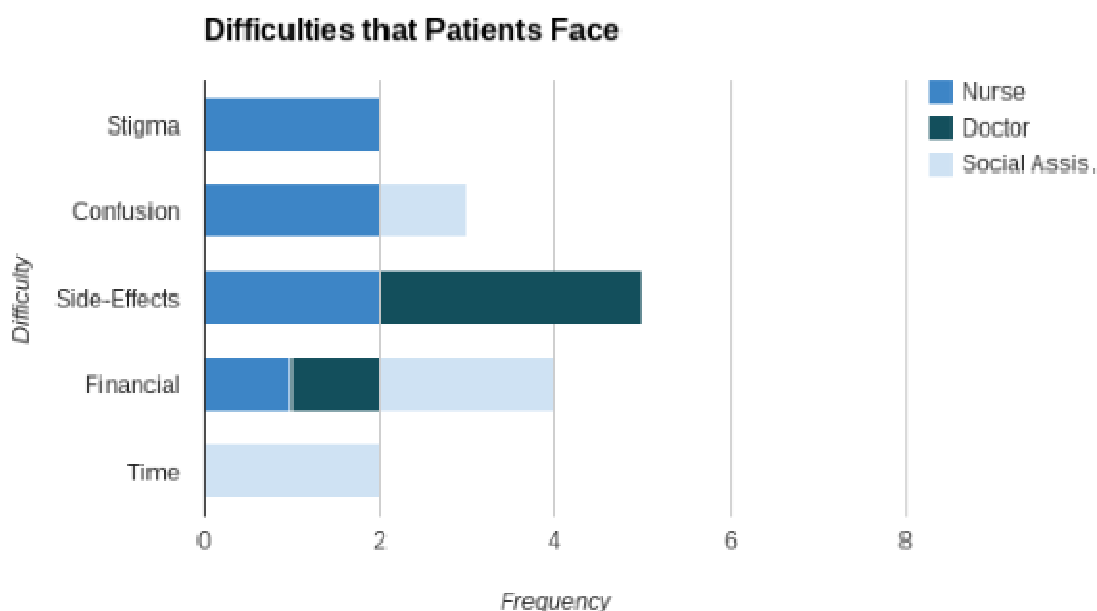


Figure 4. Professional Responses to Most Common Difficulties that Patients Face
 Demonstrates the frequency with which professionals (3 nurses, 3 doctors, 2 social assistance workers) mentioned difficulties faced by patients. Doctors were mostly in-tune to difficulties with side-effects, where social assistance workers and nurses were more likely to be aware of social struggles with treatment

Patient Response

There was no clear pattern or frontrunner to the major difficulties that patients reported experiencing. Depending on the personal situation of the patient, they would report a different major concern. Patients who were in retreatment, indicating that they had previously not completed treatment, did not show any clear pattern of difficulties, either. Only two patients out of the 16 surveyed reported stigma as a problem, making it the least important difficulty for the patients surveyed. Financial difficulties, side-effects, and inconvenience/duration of treatment were equally important to patients. Inconvenience encompasses both the six months required to complete treatment and the common complaint that it is difficult to take so many pills every day at the same time. Financial difficulties, again, were mostly reported by patients who had to come from the interior. These patients, much like the professionals, told me it was the financial trouble of travel, not the inconvenience, that was the greatest challenge for them. It is important that patients rank side-effects and duration of treatment alongside financial difficulties. Side-effects and duration are factors innate to TB treatment, and more important as inconveniences to the patient than reasons for abandonment. Six of the 16 patients still reported financial

struggles as one of their largest struggles, but many patients also responded that there were no financial struggles because treatment was free and there was free food provided.

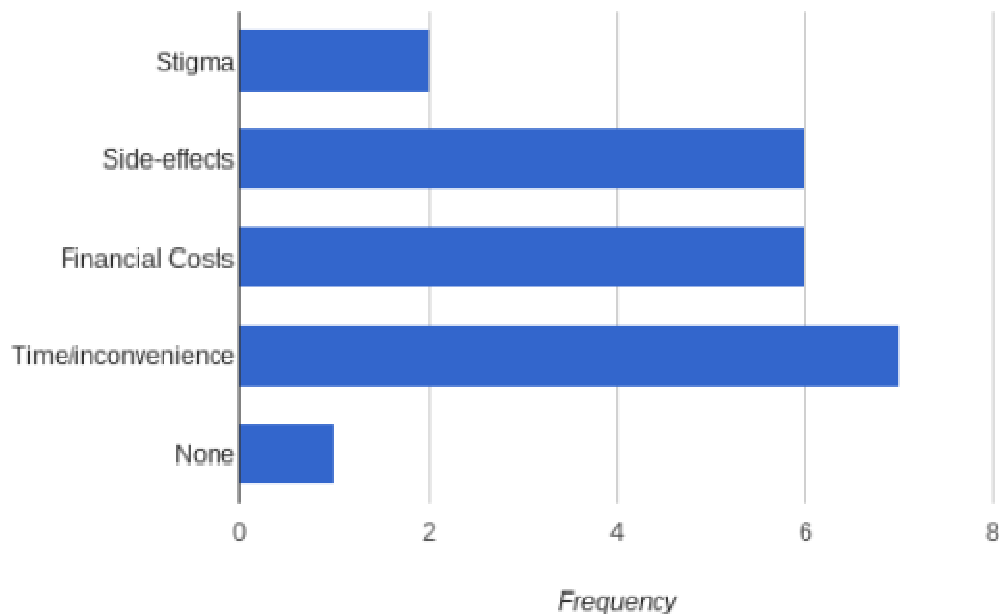


Figure 5. Patient Response to their Greatest Difficulties During Treatment

Comparing Responses

Originally, I wanted to find out what difficulties patients faced in terms of what might predispose them to abandonment. I intended to compare patient responses to professional responses to determine whether professionals were in-tune to patients' needs. The results do not answer these questions, for a couple of reasons. First of all, it is unreasonable to assume that a patient would be more comfortable divulging their true difficulties to me, a foreign researcher they do not know, than to the professionals they are so accustomed to speaking with. For example, many professionals mentioned stigma as a major difficulty patients face during treatment (see Table 2), or as an area that should be further addressed by IBIT. However, very few patients reported struggling with stigma (see Figure 5). Many, in fact, shook their head when I even mentioned stigma and told me stigma was not a problem for them at all. It is impossible for me to say which group has a better grasp of whether or not stigma against TB is a major problem; were patients uncomfortable admitting to me that they felt prejudice because of their disease? This example made it clear to me that it was futile to attempt to quantify the relationship between professionals and patients with data points, and I instead relied on interviews and participant-observation to answer this question. These results instead shed light on IBIT's commitment to patient-centric care.

Relationship between professionals and patients

Every professional that I spoke with assured me that they had an overwhelmingly positive experience with their patients, and emphasized the horizontal relationship they tried to maintain. One nurse told me “our services are very humanized. We hear the patient, listen to the patient. You see, Erin, tuberculosis is not just a disease, it has very important social determinants.”⁴ Another doctor told me, “I love [my patients]...taking care of their problems, and understanding what they are feeling, and why they are feeling [that way].” Many emphasized the importance of smiling and respecting the patient, and almost all of them mentioned that they thought patients felt comfortable coming to them with questions.

In practice, for the most part, these claims checked out. Informally in the hallways, a doctor will always stop if a patient is lost and asking where to find something, and many of the nurses are sure to greet and smile at any patients in the waiting areas. Nurses and social assistance workers I observed performing at their lecture were invested in making patients feel comfortable. Even when a patient interrupted a lecture with a comment unrelated to the current topic, the nurse in charge would stop, listen, and respond to the patient. When nurses dressed up in feather boas and oversized glasses to sing a song they had prepared about tuberculosis, patients clapped and sang along, and the environment was very happy and comfortable. At the end of the lecture, children from a local drama club performed a short, comedic play about a father whose family takes him to IBIT to get tested for TB. After the formal lecture and shows, patients were quizzed on basics that had been explained during the lecture and rewarded with treats for correct answers. The participation of the patients, both encouraged and not encouraged, seemed to validate professionals’ claims that patients feel comfortable talking about their illness and asking any questions. After the lecture, one nurse recounted a story; a man was diagnosed with TB and came to her very depressed. He asked her: why do only poor, black people in the peripheries get TB? What is wrong with their bodies? She explained to him that TB is infectious disease, and anyone can get it, although the living conditions he was subjected to put him at a higher risk. She smiled at the memory, telling me how gratifying she found it to help people understand their disease, and understand that a TB diagnosis is not a death sentence.

However, when IBIT gets busy, there are instances in which a patient might feel marginalized by their interaction with nurses. In one instance, a patient barged into the office saying he had been waiting for 3 hours, having arrived at 6:00 AM, and still had not been seen.

⁴ “Nosso atendimento aqui está bastante humanizado. A gente ouve paciente, a gente escuta o paciente, o que assim Erin, a tuberculose, ela não é só uma doença, tem determinante social muito importante.”

The nurses helped him, but did not do much in the way of apologizing. On another occasion, a mentally ill patient wandered into the building and was told that he had, again, missed his morning appointment and that he should come back the next morning. After he left the room, nurses ridiculed the way he spoke and waved his finger at the television screen, complained that he smelled bad, and told me that the man always came a few hours after he was supposed to arrive. I was surprised; their treatment of this man seemed to go against how they told me they generally treated patients. However, this was an isolated incident that I observed. Much more commonly, a nurse would argue with a patient about what they wanted to do. There was often back and forth between the patient and one particular nurse, who became visibly frustrated and would tell the patient whatever they were asking for “does not exist!” Eventually, the issue would be resolved, usually by a second nurse who would interpret the patient’s requests. It seemed to me that a patient afraid of confrontation might not want to argue with a nurse, especially if she was making them feel like they didn’t understand. Even more regularly, patients would wait in the room while nurses joked with each other or chatted on the phone. To be fair, the nurses seemed alternately overwhelmed with work; answering phone calls while multiple patients crowded into their office trying to ask questions, or without anything to do for long stretches of time while still required to stay in their offices. It is reasonable that this dynamic structure of activity might influence the way nurses interact with patients.

For every negative example, however, there is a counterexample. A nurse might go out of her way to help someone from the interior of Bahia get their lab results, even if they had shown up a day early, because it would be difficult to come back the next day. A man might stop in the office with his and greet all the nurses with hug, thanking them for helping him finish his treatment and sending a congratulatory note to his house. Many times every week, the nurses take aside new patients into a private room and give them a complete orientation to someone just diagnosed with TB, explaining the simplest details of treatment many times over to make sure the patient understands.

Evaluating IBIT as a model system

Professional Perspective

I asked professionals why they thought IBIT had lower treatment abandonment rates than surrounding public clinics, and whether or not they thought IBIT’s model was viable for the public system. I was surprised to find a large variation in their results as to the strengths of IBIT. Their answers were not restricted to just the provision of food and financial support to help offset the financial barriers to care that patients face. Instead, professionals emphasized that IBIT is patient-centric, speaking generally about the relationship that IBIT has with its patients and how

the various services they offer contribute to patients' trust in the system. Of course, the most often mentioned strength was the general provision of *acolhimento* services; some professionals described this as a “hug” and others as a “catch all”. The idea of social services is not just putting out free food for patients, but letting the patients know that someone cares about their treatment, and is paying attention. With the *acolhimento* services, it would be impossible for a patient to stop treatment and just go unnoticed.

Profession	Quality of Professional Team	Specialization	Presence of Lab	Educational Activities	Social Services	Contact Tracing	Humanized Relationship
Nurses (3)	x x	x x	x x	x	x x	x x	x x
Doctors (3)	x	x x		x x	x x		
Social Assistance (2)	x				x x		x

Table 3. Professional explanation of why IBIT outperforms the public sector

This table groups responses by profession; 3 participants are nurses, 3 are doctors, and 2 work in social assistance. An “x” represents a mention of a specific factor as a reason for treatment abandonment during a semi-structured interview

Many professionals also spoke of the relationships they had with each other, and their ability to work as an integrated team. A couple mentioned the importance of an in-house laboratory that allows patients to immediately receive diagnosis, instead of shuttling between different centers. Others brought up the importance of educating patients, and 3 brought up their humanized relationship with patients again. In response to my question, one doctor explained: “They don’t see only one professional. They see several professionals that smile at them.” Finally, contact tracing was mentioned by 2 nurses as one of IBIT’s strengths, but one doctor mentioned as one of her largest complaints about IBIT. This doctor in fact, when asked whether they thought IBIT could serve as a model for the public system seemed surprised by the idea. She told me that IBIT needed a lot of improvements before it was used as a model for any other system, mentioning that she did not think the room where she saw patients was sufficiently ventilated to prevent patients from infecting each other or from infecting her. This was the only mildly negative response I received in my interviews, and going forward for the next two interviews I asked whether professionals had any complaints about IBIT or any areas they would like to improve. In the last two interviews, both professionals emphasized they had no complaints about IBIT, although they suggested programs they thought might be helpful.

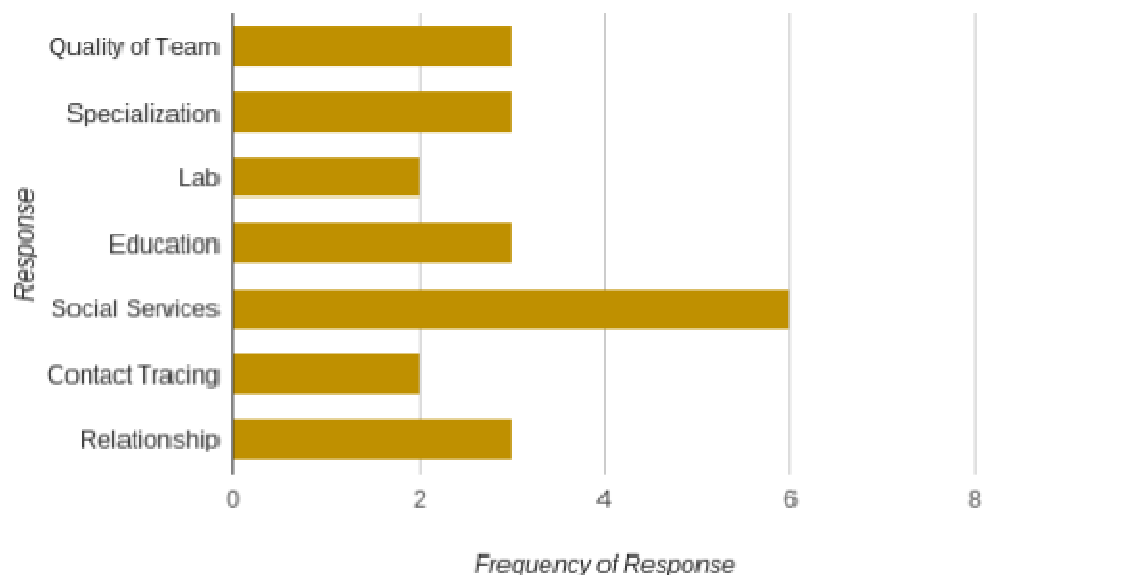


Figure 6. Professional Responses to why IBIT has low treatment abandonment rates

Patient Response

I chose to evaluate patient evaluation of IBIT's strength by asking why they had chosen IBIT. This question also helped me determine whether there was a different population that uses IBIT's services as opposed to the public sector. The vast majority of patients reported that they had chosen because of IBIT's reputation and the quality of services provided by professionals. I was surprised that no one answered that they chose IBIT specifically because of *acolhimento* services, and I wonder whether patients felt embarrassed to tell me that part of their decision to receive treatment at IBIT was due to the extra social support it provides. However, there is strong evidence from the patients and professionals that patients generally choose IBIT because they trust that they will receive quality care. A large portion of patients, 6 of the 16, told me they had not chosen IBIT but rather that it was the nearest secondary reference center for TB available to them. I did not learn as much as I hoped to from this question, but it was clear to me that IBIT has a very good reputation in the general and medial communities.

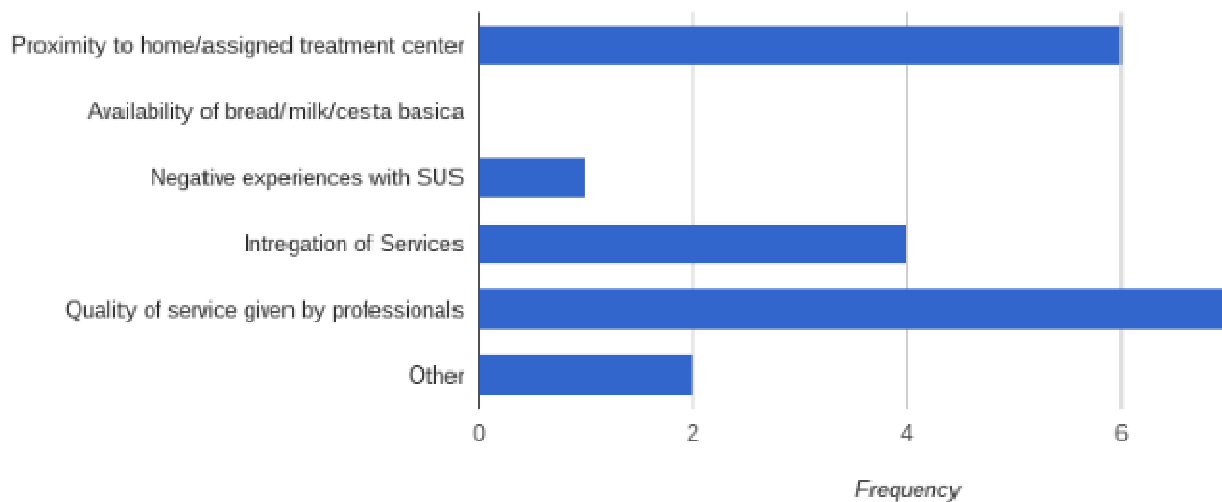


Figure 7. Patient Response to Why they Chose IBIT

IBIT's Strengths and Weaknesses

IBIT is by and large a success story, with high cure rates and low abandonment rates. It is impressive that they have adapted care to fit the needs of the patients; unlike treatment programs for other resource-poor communities, IBIT does not rely on DOTS to monitor their patients' treatment. Their success instead comes from the same horizontal relationship between patients and professionals called for by Chirina and Meirelles (2011). The staff has a culture of respect for the patient, and listening to the struggles of the patients is a priority. The horizontal relationship precedes the complementary services they provide, and create a trusting relationship between the patient and the team of professionals invested in their treatment. A smile and a call to remind a patient to come to their next appointment are a humanized approach to keeping patients in treatment, accompanied by providing food, quick diagnosis, and answering questions in a non-judgmental way when solicited. If IBIT's model is to be replicated, it will need to supersede putting out food twice a week. It requires a patient-centric approach, where structural barriers to care are illuminated through conversations with patients.

While IBIT does a good job of serving 90% of their patients, two populations seem to still need to receive more support: those who suffer from drug addiction and alcoholism, and patients living in the interior of Bahia. There are different options for trying to better provide for these populations. For addiction problems, it might be helpful to try a program like *Sputnik* that worked well for homeless, alcoholic patients in Russia (Keshavjee *et al*, 2008). Other options

include integrating services with those offered by CAPS, the mental health unit of SUS in Brazil, or providing inpatient care to drug-addicts at Hospital Octávio Mangabeira, as is done for patients with drug-resistant TB. Options for patients living in the interior of Bahia are less clear. They are the most financially impacted by treatment, as they have the highest travel expenses, and benefit the least from social services, which cannot reliably make home visits or provide bread and milk twice a week in a convenient way. One doctor had a suggestion for this; he told me that in Europe, TB had been mostly eliminated because patients were concentrated in clinics of at least 50 so that they could be seen by doctors and nurses familiar with the disease. Whether or not that is a reasonable solution in Brazil is beyond the scope of this study, but it seems like access to healthcare for those living in the interior of Bahia is a systemic problem, and likely not easy to address with a disease-specific intervention.

Conclusions

The struggles faced by patients throughout treatment at IBIT vary significantly based on the patients' personal realities, but those who live in the interior of Bahia face the largest structural barriers to care. Patients and professionals show some disparity in their ranking of difficulties, but both groups agree that side effects from medication are a common challenge, and stigma is not. Common difficulties also differ greatly from the reasons for patient abandonment; difficulties are common, and abandonment is the exception. It is still important to address common difficulties to minimize the social suffering inflicted by an institution created in order to reduce suffering. The only overlap between common difficulties and reasons for abandonment are financial difficulties, which mostly refer to patients from the interior of Bahia whose transportation costs are much higher.

Professional explanations for treatment abandonment given at IBIT generally fall into Farmer's cognitivist-personalistic pole. The only exceptions are the way some professionals view drug-addiction, alcoholism, and the desire to stop treatment as soon as TB symptoms disappear. The general consensus among professionals lists financial concerns as one of the most common reasons patients abandon treatment. This recognition is vital to the success of the program, as it allows IBIT to take responsibility for treatment default, instead of casting blame onto the patient in a diagnosis of exclusion. IBIT's system works well because it is patient-centric. It is important to note that IBIT's success is not derived from a community-based DOTS initiative, which sets it apart from other successful TB programs. That IBIT can succeed without DOTS speaks to the importance of listening to the patient over specific structuring of treatment. However, DOTS may be a more appropriate way to treat the neediest patients, that is to say, drug addicts and alcoholics whose conditions make attending regular

appointments difficult.

Future Directions for Research

I believe that this study indicates many areas that would benefit from future research. The first direction would be a more in-depth study of IBIT. An ethnographic study of the staff, who claim their relationships, their motivation, and integration lead to the success of the institution might highlight how to culture the same environment in other settings. Additionally, further delving into the changes current professionals would like to see at IBIT would be helpful. The fact that one doctor reported that IBIT should not be used as a model for the public sector indicates that some voices might not be heard. While impressive, it is worthwhile to seek directions for improvement in IBIT's structure, for example in contact tracing, patients who transfer to other institutions to complete treatment, and ventilation in doctors' offices. Finally, a more in-depth study of the most at-risk groups at IBIT, drug-addicts or patients who live in the interior of Bahia, could help illuminate areas for intervention in preventing these groups from abandoning treatment. Additionally, I think a similar ethnographic study of a public health post where tuberculosis patients are attended would be extremely valuable. Even better, experimentally providing food and other *acolhimento* services to a cohort of patients and then comparing cure rates could provide a good argument for making these services mandatory.

Glossary of Terms

Acolhimento

There is no direct translation for acolhimento in English, but it is a term often used by professionals at IBIT to describe their social support programs. These include educational lectures, checking in on patients that do not show up for treatment, congratulatory cards for those who finish treatment, individualized care and answers to questions, and the provision of food through IBIT.

Cesta básica

Cesta básica translates literally to “basic basket” and refers to a serving of food meant to sustain a family who lives below a poverty line, determined by the national government, with food for a month.

Cognitivist-personalistic barriers to care

Explanations for treatment abandonment that involve the agency of the patient, and includes but is not limited to laziness, willful noncompliance, and belief in alternate medical systems. These claims are usually not substantiated by research.

Drug-resistant strains of tuberculosis

Some strains of tuberculosis develop resistance to antibiotics after exposure to those antibiotics; that is to say, if a patient begins treatment but does not complete it, instead of killing the bacteria completely, they will allow the bacteria to evolve resistance to the drugs they had been using. This is a major concern with treatment abandonment.

Structural barriers to care

Explanations for treatment abandonment that do not involve the agency of the patient, but instead focus on societal and economic factors that interrupt a patient's ability to follow a doctor's orders.

Treatment Default/Abandonment

Both terms refer to a break of at least one month in a normal course of tuberculosis treatment.

USF: Unidades da Saúde da Família

The most basic unit of health care provided by the Brazilian unified health system, where all citizens have a right to access personalized health care.

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Appendices

ISP Reflection

1. Could you have done this project in the USA? What data or sources were unique to the culture in which you did the project?

I could not have done this project in the USA; not only does the US have an extremely low tuberculosis burden, but it also doesn't generally have entire clinics devoted to a specific disease. Part of what made this study so interesting for me is that I got a close-up look at the Brazilian healthcare system. I have heard Brazil mentioned many times in my global health classes for their admirable approaches to controlling infectious disease, and it was eye-opening to see that the system isn't perfect. I don't believe that I could have done the same study in any other country; I found that IBIT's structure was significantly different than the structure of other programs in countries with similar rates of tuberculosis, mostly because it had been adapted to cultural norms of their patients.

2. Could you have done any part of it in the USA? Would the results have been different? How?

I do not know of any tuberculosis clinics in the USA. While one might exist, most tuberculosis resources in the US are related to screening with the tuberculin skin test, catching outbreaks in homeless shelters, and screening/treating immigrants. Treatment abandonment is not a problem in the USA.

3. Did the process of doing the ISP modify your learning style? How was this different from your previous style and approaches to learning?

I have never done field research, so I definitely think the ISP modified my learning style. I came into the ISP thinking I would be doing research with a statistical outcome, and that didn't happen. I was surprised to find that I learned much more from just sitting in the clinic and talking/observing than I did from the results of any of my surveys.

4. How much of the final monograph is primary data? How much is from secondary sources?

Over half of the monograph is primary data. I found a lot of secondary data on treatment and abandonment rates for the city of Salvador, which helped me contextualize my results, and I found information on the theoretical framework set forth by Paul Farmer vital to the analysis of my own results.

5. What criteria did you use to evaluate your data for inclusion in the final monograph? Or how did you decide to exclude certain data?

I included data that shaped the way I thought about my questions.

6. How did the "drop-off's" or field exercises contribute to the process and

The drop-off prepared me for confronting the feeling of discomfort and novelty that were so common during the ISP process. I learned how to ask for help and keep my eyes open for little things.

7. What part of the RME most significantly influenced the ISP process?

I was most influenced by the individual feedback sessions we had during the RME course.

8. What were the principal problems you encountered while doing the ISP?

The biggest issue I encountered was the loss of my computer for a week. This added a lot of stress and took my focus away from my research. I couldn't work ahead as much as I would have liked, and lost a lot of time to travel to and from malls. I also struggled with the tedious nature of collecting survey responses; nurses would tell me they had 12 patients scheduled to come in, and after sitting in their office from 8AM-4PM, only two patients would have come in. This was a learning experience for me- I discovered that the surveys were not as informative as I'd wanted them to be, and I got a lot more out of observing patients interact with the nurses.

9. Did you experience any time constraints? How could these have been resolved?

Yes, I experienced time constraints in that I was not able to collect as many survey responses as I wanted, and I wasn't able to survey a random group of patients that might have represented the population at IBIT. This could have been resolved by leaving out surveys as a method of data collection and restructuring the focus of my research.

10. Did your original topic change and evolved as you discovered or did not discover new and different resources? Did the resources available modify or determine the topic?

Yes- again, I came to rely more on my participant observation as I learned to value it as a means of data collection.

11. How did you go about finding resources: institutions, interviewees, publications, etc.?

I found IBIT through a librarian who worked at the health library on UFBA's campus, and gained access to it via my mentor, Juliana. I was not able to find the statistics and information I wanted as background information until Simone taught me how to navigate SINAN and gave me background information published by the Secretaria on tuberculosis.

12. What method(s) did you use? How did you decide to use such method(s)?

I used semi-structured interviews, database searching, surveys, and participant observation. I chose the semi-structured interview so that I could prepare sufficiently to avoid language barriers and compare answers analytically, but still ask follow-up questions if desired. I chose a questionnaire to avoid inconveniencing the patients and to avoid asking them personal questions they might not be comfortable with. I chose participant observation as a way to verify the answers professionals gave me about their relationships with patients.

13. Comment on your relations with your advisor: indispensable? Occasionally helpful? Not very helpful? At what point was he/she most helpful? Were there cultural differences, which influenced your relationship? A different understanding of educational processes and goals? Was working with the advisor instructional?

My advisor was indispensable to me, mostly in that I could not have made contact with IBIT without her help. She also aided in preparing my consent forms, translation, analyzing results, and printing materials. There were not a lot of major cultural differences, as she is currently pursuing her PhD in the epidemiology of tuberculosis, so she was on the same page as me in terms of showing up at expected times and reporting results in an academic way. I was also excited to work with her as I have often considered doing post-graduate work in the epidemiology of tuberculosis, and it was exciting to meet someone actively involved in that.

14. Did you reach any dead ends? Hypotheses which turned out to be not useful? Interviews or visits that had no application?

The biggest dead end I faced was my survey. I had a small sample, and did not really have a clear pattern to my results. However, I believe this is a result in itself and I was able to use my other methods of data collection.

15. What insights did you gain into the culture as a result of doing the ISP, which you might not otherwise have gained?

While I had already witnessed the incredible patience people have with their health system in Brazil, I was astounded at the lack of complaints at IBIT. To me, everything seemed very slow, social, and inefficient, yet they emphasized to me over and over again how quickly they worked. People did not complain about the hours they had to spend waiting to see a nurse just to have her tell them they were in the wrong office- had I been in their shoes, I would have been extremely frustrated.

16. Did the ISP process assist your adjustment to the culture? Integration?

Yes, the ISP was my largest exposure to other Brazilians my own age. I spent a lot of time with nurses 20-25 years old who would often congregate in the office I waited in for patients, and who regularly went to lunch with me. I had a lot of really valuable conversations with them that had nothing to do with my ISP.

17. What were the principal lessons you learned from the ISP process?

I learned the importance of preparation. I wish I had thought about how I might analyze my results before I began collecting information.

18. If you met a future student who wanted to do this same project, what would you tell them?

I would tell them to focus on the anthropological aspects of data collection when designing their study. I would also tell them to try to talk to people in the field before deciding what issue they want to study- I found out about a lot of interesting issues (drug-addiction, poor record keeping and transferences, discrepancies in whether stigma is a serious problem, care for those living in the interior) after I had already begun my study, and I felt restricted by looking at treatment abandonment.

19. Given what you know now, would you undertake this, or a similar project again?

I might slightly alter my project to more formally focus on either professionals or patients, but I was very happy to be able to study the functionality of tuberculosis clinic. I am excited to carry out more public health research, although in the future I want to explore more epidemiological work rather than anthropological.

Termo de Consentimento Livre e Esclarecido

Prezado(a) Senhor(a)

Gostaríamos de convidá-lo a participar do estudo **“Dificuldades no processo de tratamento da tuberculose: olhar do serviço de saúde e de seus pacientes”**, que tem como objetivo **avaliar as dificuldades no processo de tratamento da tuberculose quanto à prevenção do abandono, sob o olhar de uma fundação assistencial ao tratamento e de seus pacientes, em Salvador-BA**. O referido estudo será desenvolvido por **Erin Slatery** e orientado pela **Prof^a. Juliana Cantalino**.

A pesquisa consistirá na realização de entrevistas, observações e participações junto aos participantes do estudo e posterior análise das mesmas. Será conduzida dessa forma, pois pretendemos entender a experiência vivida dos participantes.

Garantimos que a qualquer momento da realização desse estudo qualquer participante e/ou estabelecimento envolvido poderá receber esclarecimentos adicionais que julgar necessários. Qualquer participante selecionado ou selecionada poderá recusar-se a participar ou retirar-se da pesquisa em qualquer fase da mesma, sem nenhum tipo de penalidade, constrangimento ou prejuízo aos mesmos. O sigilo das informações será preservado através de adequada codificação dos instrumentos de coleta de dados. Especificamente, nenhum nome, identificação de pessoas ou de locais interessa a esse estudo. Todos os registros efetuados no decorrer desta investigação científica serão usados para fins acadêmico-científicos e inutilizados após a fase de análise dos dados e apresentação dos resultados finais na forma de monografia ou artigo científico.

Em caso de concordância com as considerações expostas, solicitamos que assine este “Termo de Consentimento Livre e Esclarecido” no local indicado abaixo. Desde já agradecemos sua colaboração e fica aqui o compromisso de notificação do andamento e envio dos resultados desta pesquisa.

Erin Slatery
Estudante no Programa do SIT Study
Abroad: Brasil-Saúde Pública, Raça e Direitos
Humanos

Profa. Juliana Cantalino
Orientador(a)

Eu, _____, assino o termo de consentimento, após esclarecimento e concordância com os objetivos e condições da realização da pesquisa “Dificuldades no processo de tratamento da tuberculose: olhar do serviço de saúde e de seus pacientes”, permitindo também, que os resultados gerais deste estudo sejam divulgados sem a menção dos nomes dos pesquisados.

Salvador, ____ de _____ de 2014.

Assinatura do Pesquisado(da)
Pesquisada

Qualquer dúvida ou maiores esclarecimentos, entrar em contato com a responsável pelo estudo:
e-mail: gabriela.ventura@sit.edu **Telefone:** (71) 9982.2718 ou andreiasantos72@hotmail.com (do SIT Study Abroad: Brasil-Saúde Pública, Raça e Direitos Humanos).

Semi-Structured Interview Questions

- Qual é o seu cargo e função profissional no IBIT? / What is your job and professional function at IBIT?
- Há quanto tempo você trabalhou para IBIT?/ How long have you worked for IBIT?
- Por que você decidiu trabalhar aqui? /Why did you decide to work here?
- Como é sua relação com os pacientes? / What is your relationship with patients like?
- Porque você acha que os pacientes abandonam o tratamento? / Why do you think patients abandon treatment?
- Quais são as principais dificuldades e queixas dos pacientes durante o tratamento?/What are the principal difficulties and complaints that patients have during treatment?
- Por que os serviços públicos não adotam o modelo do IBIT? Você acha que o modelo é viável para o SUS?/ Why don't public services adopt IBIT's model? Do you think IBIT's model is viable for SUS?

Questionário Para o Paciente/Patient Survey

1. Número do questionário _____ / *Number of Questionnaire*
2. Idade _____ / *Age*
3. Sexo/*Sex*
 1. Masculino/*Male*
 2. Feminino/*Female* _____
4. Por quanto tempo você está em tratamento? (em meses) _____
5. É a primeira vez que você foi diagnosticado com tuberculose? *Is this the first time you have been diagnosed with tuberculosis?*
 0. Não/*No*
 1. Sim/*Yes*
6. Você está em tratamento para alguma doença crônica (diabetes, HIV/AIDS)? */Are you currently in treatment for another chronic disease (diabetes, HIV/AIDS)?*
 0. Não/*No*
 1. Sim. Qual? _____ / *Yes. Which?*
7. Como você ficou sabendo sobre o IBIT? */How did you find out about IBIT?*
 - () Boca a boca *Word of Mouth*
 - () Anúncios/*Advertisements*
 - () Encaminhado por outro sistema de saúde/*Sent by the health system*
 - () Outro. Qual? _____ *Other (which?):*
8. Por que você escolheu IBIT? (marcar todos que se aplicam) */Why did you choose IBIT? (mark all that apply)*
 - () Proximidade de casa/trabalho/*Proximity to house/work*
 - () Disponibilidade de cesta básica/pão e leite de soja/*Availability of cesta básica/bread and soy milk*
 - () Experiências negativas no passado com SUS/*Past negative experience with SUS*
 - () Integração de serviços (diagnóstico, educação, tratamento) */Integration of services (diagnostic, educative, treatment)*
 - () Qualidade da assistência dada pelos profissionais/*Quality of services offered by professionals*
 - () Outros. Quais? _____ */Others. Which?*
9. Qual é a parte mais difícil do tratamento? (escolha até 3) */What is the hardest part of treatment (choose up to 3)*

() *Estigma/preconceito da comunidade e/ou da família/Stigma/prejudice from the community or family*

() *Os efeitos colaterais dos medicamentos para tuberculose/Side-effects of drugs for tuberculosis*

() *Os custos financeiros do tratamento (inclui faltar ao trabalho, transporte, etc)/Financial costs of treatment (includes missing work, transportation, etc)*

() *Tempo disponibilizado para tratamento/Time taken up by treatment*

() *Outros (quais?):/Others (which?):*

Semi-structured Interview Responses

Profession	Years at IBIT	Relationship with Patients	Why do patients abandon treatment?	Common Complaints of patients	IBIT's strengths
Nurse/Researcher	18 yr	<ul style="list-style-type: none"> -Human and friendly -makes an effort to not wear a mask and give hugs -believes a good relationship with the patient is an important part of treatment success 	<ul style="list-style-type: none"> -Transferred between units -Unreliable staff and lack of trust in the medical system -drug addicts -homeless -these last two have low self esteem, and lack of interest in treatment 	<ul style="list-style-type: none"> -stigma and belief that they are going to die, confusion 	<ul style="list-style-type: none"> -Communication and trust within a team of professionals who work for the patient -Education to make sure patient understands they have TB and there is a cure -Contact tracing -Lab in house (efficiency) -specialized in TB -care about patients
Nurse Coordinator	6 yr	<ul style="list-style-type: none"> -very good, very humanized -here at IBIT a good relationship is common, it's a goal -wants to understand, listen, and respect 	<ul style="list-style-type: none"> -drug addiction -alcoholism -homelessness caused by drug addiction (frames these as social difficulties) 	<ul style="list-style-type: none"> -drug addiction -side effects of drugs -stigma 	<ul style="list-style-type: none"> -acolhimento -presence of laboratory -have not really studied it, just seems like theirs works better
Social Assistance Director	14 yr	<ul style="list-style-type: none"> -finds work gratifying, congratulates patients who finish with a card -positive experience, they ask her questions comfortably 	<ul style="list-style-type: none"> -drug addiction -alcoholism -financial difficulties -lack of organization in public sector 	<ul style="list-style-type: none"> -lack of understanding about disease -financial difficulties 	<ul style="list-style-type: none"> -organization -social services -independent funding
Nurse Technician	22 yr	<ul style="list-style-type: none"> -good for the most part, 	<ul style="list-style-type: none"> -alcoholism -drug addiction 	<ul style="list-style-type: none"> -misconception 	<ul style="list-style-type: none"> -contact tracing -social services

cian		although some people thinks she is too strict	-live far away -feel better and want to stop	s -stigma	
Social Assistance Worker	3 mo	-good, they come in depressed and with low expectations and she helps them understand how to/they can get better "bastante positivo"	-socioeconomic problems: financial difficulties -drug and alcohol additction? -Think negative smear means they are better -some forget appointments -adolescence	- socioeconomic problems -it's hard to come every month	-treating TB as pscychological and physical -acolhimento
Doctor/ Epidemiologist	7 yr	-Good, he likes working with them "I love them" -Wants to understand how they are feeling	-Alcoholism -Drug Addiction -Financial Concerns -Do not like to follow prescription -Feel better and want to stop	-not enough money to get to the clinic -side-effects of drugs (nausea, vomiting)	-Follow-up to make sure they show up -Offering food -Seeing a team of integrated professionals, not just one person -know disease well
Doctor/ Epidemiologist	15 mo	-Good generally -patients wear masks if she asks them politely	-Drug addiction -Lack of family support	-gastronintestinal side effects	-does not think IBIT is a good model at all, needs to improve: -seeing TB and asthma patients separately -protecting the doctor -investigation of contacts -education of patients
Doctor	55 yr	-does his best to explain to them that they cannot abandon treatment	-drug addicts and alcoholics abandon -people in the interior feel better and can't afford to come back -people feel better	-length of treatment -taking medicine every day -Good nutrition -Don't sleep	-explain to patients that they cannot abandon -provision of free food - history/specialization of the clinic

			and think they can stop	well -Want to go to the beach, but he suggests against it	
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Survey Responses

Survey Number	Age	Gender	Months in Treatment	Retreatment	Co-morbidity	How heard about	Why chosen	Greatest Difficulty
1	48	2	3	0	0	3	5	2,3,4
2	19	1	2	0	0	1	4	4
3	67	1	5	0	0	3	4,5	1,4
4	62	2	2	0	0	3	3	2
5	23	2	3	0	0	3	5	3
6	22	1	6	1	0	1	5	4
7	69	1	5	1	0	3	1	1
8	27	2	3	0	0	3	4,5	2,4
9	50	2	3	0	1	3	1	2
10	24	1	4	1	0	3	1	3
11	32	2	2	0	0	3	5	2,3
12	49	2	2	0	1	3	1	4
13	22	2	4	0	0	1	4	2,4
14	35	1	3	0	1	3	5	3
15	48	1	2	1	1	1	6	3
16	40	1	5	1	0	4	6	5

Key:

Gender: 1-male, 2-female

Retreatment: 0-first diagnosis, 1- in retreatment

Co-morbidity: 0-no co-morbidity, 1-has comorbidity

How heard about: 1-word of mouth, 2-advertisement, 3-sent by health system, 4-other

Why chosen and Greatest Difficulty: See questionnaire, ordered chronologically