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Multiple tuberculosis: a praxiography at the Instituto Clemente Ferreira, in São Paulo (SP), Brazil

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This article proposes to present how tuberculosis is enacted at Clemente Ferreira Institute, a public health institution in São Paulo, Brazil, that is the primary healthcare city reference for most serious TB cases. By admitting that the disease is multiple, and that it is brought into existence through the practice of a number of different agents, we decided to follow up both patients and health professionals in action in order to identify versions of tuberculosis that acted at the institution's limits. In this article, it has been possible both to reveal different versions of a single illness and also to observe how these different versions distribute and coordinate themselves. As such, they not only configure tuberculosis itself; they also determine how points of conflict occasionally occur through the encounter of various forms of disease production.

Keywords: Tuberculosis. Multiple realities. Praxiography.

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Introduction

Tuberculosis is a worldwide public health problem because it presents the highest mortality rates among infectious diseases[1,2]. In 2016, according to data from the World Health Organization (WHO), 10.4 million people were affected by tuberculosis and more than one million died as a result[3]. In Brazil, the situation is no different, even though the country has effective means of diagnosis and treatment. Each year are registered 69,000 new cases of tuberculosis, with 4,500 of them resulting in death[4]. It is a complex disease that involves historical, socio-anthropological and political dimensions that have instigated several researchers.

In the field of Social and Human Sciences, several authors[5-10] proposed to study tuberculosis. We may highlight among them the studies by Gonçalves[11-14] who carried out studies exploring topics such as the trajectory of tuberculosis in Brazil, the policies to control the disease and the adherence to therapies against tuberculosis. Pôrto[15-17] has developed research on the history and social representation, especially analyzing the stigma and prejudice that involve people carrying the disease. Bertoli Filho[18] reflected on individual and collective behaviors in the face of the disease by mixing literature and scientific discourses. The approaches of the social and human sciences are thus contributing to the knowledge of tuberculosis in Brazil.

In this text we aim to approach tuberculosis based on a praxiography performed at the Clemente Ferreira Institute (ICF). Praxiography is a type of ethnography that considers, in addition to meanings and perspectives, the breadth of the agents involved and the materialities mobilized for the construction of realities. We chose to use the theory of Mol[19] on praxiography and multiple realities because we rely on the power of this proposal for the understanding of tuberculosis in Brazil. Tuberculosis presents so many topics and details, as suggested by the intricate analysis mentioned above, that there is no way to approach everything. We needed to choose a path, not because there is only one direction to go with advantage, but because, as Geertz pointed out "there are many: it is necessary to choose"[20] (p. 15).

We will then start by briefly presenting the place that served as the setting for this study.

The Clemente Ferreira Institute

As a tertiary reference center in the treatment of the most serious cases of tuberculosis, which cannot be followed up solely by the Basic Health Units (BHU), ICF is the main treatment center of the disease in the city of São Paulo and one of the main centers in Latin America. Located on a very busy avenue, the building sitting in the midst of high-rises stands out for its ample and wooded spaces. Since its foundation in 1913, ICF has actively participated in projects and research allowing advances in the diagnosis and treatment of tuberculosis[21].

Following the hygienist conceptions of the 19th and 20th centuries, the architecture of the ICF resembles the European dispensaries of the same period[22]. It has three floors with large doors and windows surrounding a rectangular solarium, allowing for excellent circulation of air and sunlight in all rooms to assist in the treatment of tuberculosis and decreasing the chances of transmission of the disease (Figure 1). Currently the available services are divided as follows: the ground

floor houses the diagnostic laboratories and clinical analysis, the Department of Epidemiological Surveillance, the Medical Records and Statistics Service (Same) and a locker room for ICF professionals. On the first floor are the reception, pharmacy, medical offices, nursing, nutrition, social work and psychology services, emergency rooms, waiting rooms, clinical and administrative board, as well as toilets for employees and patients separately. A few flights of stairs up there are more rooms that make up the ICF administration; staff's lunchroom and a meeting room.

Figure 1. Clemente Ferreira Institute.

Wikimapia[23].

After presenting the ICF, it is important to highlight the objectives of this article: (i) to understand how tuberculosis is *enacted* (or acted, staged, performed - possible translations of the verb *to enact*, used by Mol[24]) at the Clemente Ferreira Institute; (ii) to capture how the practices of different agents, of the Clemente Ferreira Institute, perform various versions of the disease and how they coordinate in the configuration of what is tuberculosis itself. By following the way it was performed (*enacted*), we find that it is not a single object to which only different meanings are attributed, we also identified that it can be manipulated and transformed by different practices, becoming thus a multiple disease.

Based on the observation of patients and health professionals in action - prioritizing, instead of the difference of perspectives, collaboration between them -, we seek here to reach an understanding of the dimension of the reality of tuberculosis. We believe that by identifying the different ways of doing tuberculosis and how its different versions coordinate we can identify possible conflicts or dissonances that may occur in this process.

Next, we present in more detail the methodological movement used as theoretical support for the development of this work.

Methodology

This article is the result of a larger work. This is a part of the results of a praxiography performed during seven months, between June and December 2014. During this period the first author followed every day the routine of professionals and patients of the ICF, recording the way they performed (enacted) multiple versions of tuberculosis that connected during their encounters. As we shall see below, realizing the existence of the various versions of this same disease and the way they connect and interfere with each other was essential to understand tuberculosis and its consequences as the treatment and the logic that prevails over it.

In this work we will focus on the multiple versions of tuberculosis performed (enacted) in ICF. For this purpose, we adopt the concept of multiple reality defined by Mol[19]. As her proposal, theory and method can never be separated, and the starting point is the theory that the author presents in her book "The Body Multiple: Ontology in Medical Practice"[19].

In this work, Mol does research in a Dutch hospital during the treatment of people with arteriosclerosis in the vessels of the legs. There is one question that guides all of Mol's work: How is atherosclerosis done? For the author, reality is not given as a priori, but is shaped along the practices of different agents. It is not enough to express opinions and meanings to objects of study, which she believes exist only because they can somehow be manipulated. In other words, they persist because they are handled by certain agents in the context of their practices[19,25,26]. Thus, if objects are effects of practices, therefore different practices make various objects. For example, in the case of the Mol study, the diagnosis of atherosclerosis in the medical clinic is based on patients' complaints when they feel pain in walking, as a result of the decrease in blood flow in the leg vessels and also in the increase in their perceivable temperature during physician's palpation. In the pathology laboratory, it is performed on the atheroma adhered to the inner part of the blood vessels. Several versions of atherosclerosis are then enacted, which is why Mol qualifies reality as being multiple. It is important to note that this does not mean that these versions are disconnected, on the contrary, "they are more than one, and less than many"[19](p. 8). Its various versions have some relation and connect with each other; its singularity, represented by the unique category called atherosclerosis, is the result of an effort of coordination among many practices[19,27,28].

Mol shows that when we come to understand the objects of study according to the way their versions are performed by the most varied practices, it is clear that knowledge is no longer a statement about the true reality, but a practice that interfere with other practices. Mol thus attributes a new meaning to ontology. The term is mobilized into the plural and "is no longer something that precedes knowledge, but is something that is done, staged or performed in the process of apprehending and knowing"[24] (p. 300).

In order to develop his work, as mentioned above, Mol adopted praxiography, a research method that is not only concerned with the interpretation of meanings or perspectives, but also considers materialities (e.g. microscopes, sphygmomanometers, among others) that are activated by agents to perform their objects[19,29,30]. The study of practices allows exploring the interactions between material and social elements. Additionally to the importance of what these agents think about a particular object of study, it becomes equally relevant: what they do, how they do it and with what

they do, since the realities do not exist by themselves, but they bring together a set of heterogeneous elements: people, objects, words, papers, machines and etc[31].

Based on this theoretical framework our purpose was to understand how the practices of different professionals and patients performed (enacted) tuberculosis in ICF. The institution has an interdisciplinary team of professionals and a complete structure to attend patients with multidrug-resistant tuberculosis with serious adverse effects to medication, comorbidities and special treatment schemes. It is not open to walk-ins, so the admission of patients is done through referrals from other health services, such as BHU and hospitals.

We have adopted pseudonyms in the next section of this text, to ensure anonymity and confidentiality of our interlocutors. After being informed about the research objectives, all of them signed the Informed Consent Term. Once all the requirements were fulfilled, the Research Ethics Committee of the Federal University of São Paulo approved the research under report 567.074/2014.

Results and discussion

Using Mol's[19] proposal as a starting point, the disease is performed (enacted) in the course of different practice contexts, along the progress of our observations in the ICF. As we got in and out of the office rooms and up and down the stairs, we noticed that tuberculosis was multiple, not restricted to being just an infectious disease. Different versions circulated in that space, depending on where you were and on the availability of materialities.

To expose these different versions, the following narratives will follow the pathways determined by the ICF related to the care of patients with tuberculosis. The first step is done in the nursing pre-consultation room, where vital signs (temperature, blood pressure, oxygen saturation, weight and height) are measured. Located on the first floor, the room has a table and two chairs, one for the patient and one for the nurse. The existing material is restricted: a scale, a sphygmomanometer, an oximeter, a thermometer, alcohol and cotton. As the nurse checks the signs, the patient asks the results and compares it with the previous indices. We note an intriguing moment for most patients: the body weight in the balance. As soon as the numbers appear on the display, a version of tuberculosis is performed (*enacted*). This is what we observed in José.

José is a resident of the eastern region of São Paulo city, 30 y.o. in his third month of treatment for "a lung disease." In all the consultations, his current weight was checked and wrote down by the nurse on her chart. At the same time, he would take a notebook from his pocket, record the weight, and compare it with the differences in whether he had gained weight or lost weight from one month to the next. According to him,

> We lose too much weight. Lord, it looks like we are disappearing. All the bones appear, we completely lose strength [...]. Sitting in a chair for a long time is a sacrifice. I'm glad I'm getting a little bit of weight back [...], so the people do not escape from me anymore and I'll go back to normal. (José)

In the version that José's illness performed (enacted), with the help of his notebook and the nurses' scales, tuberculosis manifested itself in the apparent emaciation of the body, as well as in the weakness and fear it might cause in other people. The report of the corporal modification and the weakness due to the tuberculosis is common and shows that these symptoms are indicative that something is not well and that it is necessary to seek help, whether it is medical or spiritual, as evidenced in the studies of Gonçalves[12,14] and Jung et al.[32].

José's version sum up with several similar versions from other patients, as we found out later. Leaving the nursing pre-consultation, the patients waited for the medical appointment in the waiting room or on the balcony facing the solarium. We found Arnaldo, 48 y.o. on this porch, and as we talked, the conversation allowed us to identify more versions of tuberculosis. A black, medium height, married man, living with his wife, a daughter and a grandson in a two-room house, a house built by himself in the backyard of his father-in-law's house, in the neighborhood of Jabaquara. He has been a bricklayer since he was 18 when he left school to start work and "help at home". While we were talking to him and his wife, Dr. Deise called him to come in. When we asked Arnaldo if we could accompany him, he motioned for us to follow him.

He and his wife sat in the chairs next to the table of the infectious disease doctor. In the open file on the table, along with the documents sent by BHU, there was a conjecture of tuberculosis. Due to difficulties in diagnosis, Arnaldo was then referred to the ICF. Dr. Deise asked him what had happened and what he was feeling. When responding, he performed (enacted) a version of tuberculosis similar to that of patient José:

> A few months ago I started to slim down, even eating well. But then, well, I started to lose weight and get weak too. Weak, really weak. Even so, I was going to work. You know, you cannot stop, right? because you have commitments? But there was a day when I was no longer holding on and I left work early. Then, when I got off the bus in front of the house, I fainted from being so weak [I was]. The people assisted me, took me home and there was no choice: I had to go to the medical post that is near my house. They said it might be a lung business, but they were not sure, so they sent me here. That's it, doctor, weakness, you know, I cannot work, a bad body, I get sweaty too. (José)

Still during the anamnesis, the doctor asked him if he coughed. At the same time, with the stethoscope on Arnaldo's chest and back, she would listen to his lungs for "caves," or other findings that might indicate the action of tuberculosis bacilli, scientifically known as Mycobacterium tuberculosis. Arnold replied that he coughed, but not continuously. He did not seem to realize that he coughed, or did not attribute to this symptom the same importance as the doctor. Dr. Deise still talked about symptoms like night sweats, fever in the afternoon, but he insisted on mentioning "body weaknesses."

As soon as Arnaldo and his wife left, we stayed in the office to talk to Dr. Deise. She reinforced that the patient's symptoms were clear indication of pulmonary tuberculosis: cough for more than a month and sweating. This was confirmed by the words of Arnaldo's wife: every day in the morning, it was necessary to change

the bed linen. To complete her diagnosis, the doctor looked in the patient's chart for radiological exams sent by BHU that had sent Arnaldo to the ICF. On the negatoscope - a white rectangular apparatus that emits a white led light -, Dr. Deise placed the X-ray of Arnaldo's lung spending some time analyzing the image in front of her. Suddenly she showed us a finding, what she had called "caves," that is, the cavities in the thicker walls of the lung that represented the action of disease. He said that with the aid of the stethoscope it was possible to hear sounds indicative of the presence of "caves" and also of accumulation of secretions in Arnaldo's lungs.

As Mol[19], who describes the various versions of atherosclerosis that were performed (enacted) at the Z Hospital, we were also able to identify, within the ICF, what may be called multiple tuberculosis. For José and Arnaldo, tuberculosis existed to the extent that they could not "take care of life" because of the emaciation and weakness of their bodies. In Deise's office, another version of the disease was performed (enacted) concurrently with coughing for more than three weeks, from evening fever, night sweats and "caves."

At this point in the text, it is important to note that Mol cares about linguistic repertoires. According to her, regardless of context, some language artifice is used in people's moments of interaction. A doctor cannot make a diagnosis just by imaging tests, the patients need to talk about what they feel and what they think about the symptoms. Working with the idea of versions of a single reality does not mean excluding perspectives, but rather - instead of emphasizing the difference that is between them - prioritize collaboration between the various actors, in which each one, with their version, makes up the multiple reality[24]. In addition, we must remember that Mol never ignores the microscopes, reinforcing the value of the materialities that make visible the profuse versions of the disease and enable us to manipulate it[19]. Thus, the balance in the nursing pre-consultation room, Arnaldo's book, stethoscope, X-ray, and negatoscope attached to the wall of Dr. Deise's office help to enact tuberculosis, making it visible.

At ICF, after the medical consultation patients wait for the nursing post-consultation, when they are advised about the use of the medication and sent to perform complementary tests in order to confirm the diagnosis of tuberculosis and to evaluate the evolution of the disease. It should be noted that, at the time of this research a series of reforms were ongoing at the ICF. As the X-ray room was disabled, the patients were sent to other radiological services, which prevented us from following up the examination and to evaluate how the tuberculosis was enacted in the imaging room.

In the laboratories for the bacilloscopy and also in the epidemiological surveillance room, patient, disease and treatment data were cross-referenced for analysis in order to detect other distinct forms of tuberculosis. Bacilloscopy, also known as sputum examination, is designed to identify patients with bacilli, who are able to release the etiologic agent of tuberculosis by infecting other people, as well as to monitor the progress of tuberculosis treatment. Thus, the absence of bacilli in the test means that the treatment is being effective.

The causative agent of tuberculosis is scientifically called *Mycobacterium tuberculosis* and popularly known as Koch's bacillus. It is a mycobacterium that has alcohol-acid resistant properties (BAAR), that is, it is able to retain dyes even after

washing. Thus, during the sputum examination, the laboratory technicians who carry out the examination look for BAAR in the smears ("red dots" that appear in the microscopic field - Figure 03), as explained by Mariana, the lab technician.

After taking all the individual protection care measures, Mariana began to prepare the material for the examination. The sputum was collected in small clear plastic recipients with red cap, and then sent directly to the laboratory identified with the patient's full name and the patient's medical record number. The technician began its work by completing the exam request sheets with data referring to the appearance of the contents of each recipient. After completing all the data, she began to prepare the slides that would be analyzed later by means of the microscopes arranged on a workbench.

Mariana worked very cautiously, handling everything very slowly. According to her, any fast movement could form aerosols, very light particles containing Koch's bacilli that may remain in suspension in the air for a long time. This increased the risk of contamination - by inhalation - of the people who worked there.

After opening one of the pots, which contained a purulent-looking secretion, Mariana put some of the contents on a transparent sheet with a matte band containing the number corresponding to the record form she had filled before the test. The sample was spread across the glass slide with reciprocating movements, a procedure she called "distension." After allowing it to dry at room temperature, the technique passed the slide over a flame to help fix the smear (slide plus the sputum). Soon after, the stage of coloring of the material began by means of the technique called Ziehl-Neelsen, allowing the identification of BAAR. In this technique, the slide was colored with a substance called fuchsin and then discolored with an alcohol-acid solution. After washing, methylene blue was added to the slide, and the sample was then ready to be read. Mariana divided the microscopic field into imaginary quadrants and counted how many "red dots" (BAAR) appeared in each one and noted on a graph paper. According to the average number of BAARs found in each quadrant, results may be graded as: negative, when there were no BAAR; positive, when one to nine were found in 100 fields; positive +, from 10 to 99 findings in the 100 fields; positive ++ if one to ten are found in the first 50 fields; positive +++ if more than ten are identified in the first 20 observed fields. Bacilloscopy was performed throughout the treatment and every six months or a year, even after the patient was cured, to monitor for possible reinfection.

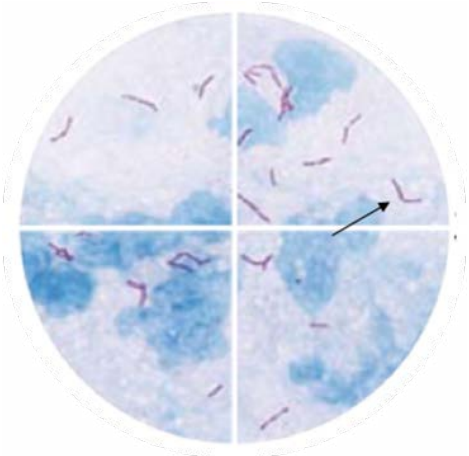

Figure 2. Microscopic field showing "red dots" (BAAR)[33].

We observed that in this version of tuberculosis, the *Mycobacterium tuberculosis* could be seen through the "red dots", identified with the help of a microscope. It was quite different tuberculosis from those that performed (enacted) on the first floor of the ICF. This version, once outside the limits of that laboratory, circulated along with the other versions throughout the service in the form of a positive or negative examination result.

On the opposite side, with the help of statistical programs and several information sheets (patient information, test results and data on the progress of each treatment), epidemiologists of the ICF Epidemiological Surveillance enacted a "difficult disease." The high incidence of tuberculosis, common in the most peripheral regions of the city, affects people with low income and with little or almost no schooling. In addition, treatment is long and requires high adherence in order to avoid death. The relationship between tuberculosis and poverty is well documented. Studies such as Rocha's; Adorno's[9] and Santos' et al.[34] reveal that in Brazil, tuberculosis is synonymous of a socially determined disease.

We realized that as the arteriosclerosis studied by Mol[19], Tuberculosis is also a multiple disease that arises from the different ways it is enacted in various contexts. In frame 1, below, we seek to illustrate the various versions of tuberculosis found in the ICF. We must emphasize that nutritionists, social workers, nurses, among other professionals, are also part of a process not described in the text, which is why they are only placed in this Framework.

As already mentioned, a multiple disease does not mean the existence of an indefinite number of excluding versions and disconnected bodies. On the contrary, a multiple disease indicates that these versions have some kind of connection, overlapping each other to form a single category in a later step[19]. All versions of tuberculosis identified by the study in the spaces of the ICF were interrelated forming a singular tuberculosis. This merging movement of the different versions of an object is called coordination by Mol. Since tuberculosis must be diagnosed and treated, versions that are practiced in doctors' offices, laboratories and patients themselves – both with advances and setbacks - are coordinated to constitute a single category for making therapeutics possible.

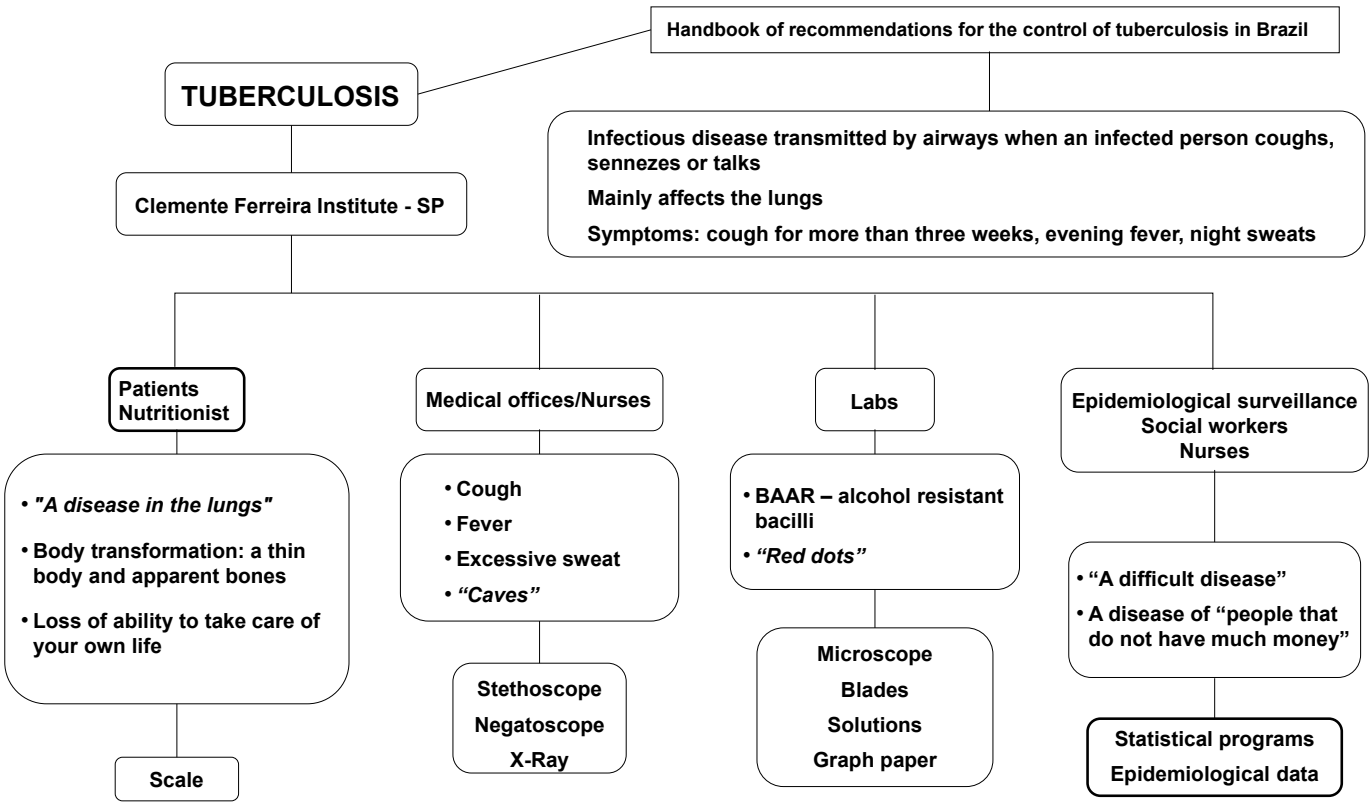

Figure 3. Tuberculosis Versions as found in ICF during fieldwork.

Elaborated by the authors based on Annemarie Mol's[19] theory of Multiple Reality and the Handbook for Tuberculosis Control Recommendations in Brazil[35].

Also according to Mol[19], this coordination does not always occur in a balanced way, and there may be inconsistency between the different versions of the disease making this movement unfeasible. She cites as an example the fact that the result of an examination does not correspond to the hypotheses of the doctor in his office. In the case of this research, we observed that incongruences occurred in this movement that could delay the treatment of tuberculosis for a while.

It is the case that the version of tuberculosis performed by the patient who cannot be complemented with that of the doctors and vice versa. During the research, for example, we find patients who, after overcoming the weaknesses and corporal modifications caused by tuberculosis, do not find the use of medications necessary anymore. For the medical team, even if the symptoms have disappeared, this does not mean cure leading them to keep the treatment. When there is no way to coordinate these two versions, the result is that the treatment is not done properly for a period or is discontinued by the patients. We are addressing here the adherence to treatment for tuberculosis. This subject was competently approached by several authors[6,9,36], resting to the authors to add that this failure in the coordination movement is not and should not be permanent. To Mol[19], in the case of diseases that need to be cured, agents will

seek resources, alternatives, and other modes until their versions co-ordinate and treatment becomes possible.

The different versions of tuberculosis performed in ICF were not limited or locked inside the spaces of their formation. By circulating throughout the Institute, everyone had access to them through each patient's medical records as they moved from one location to another. In a brown paper file, gathering evolutions of the most varied health professionals and also of the lab tests, the different versions of tuberculosis practiced in the ICF condensed and moved from one room to the other.

Final considerations

At the end of this article, we sought to identify and describe the different versions of tuberculosis performed in ICF. During ethnography, we perceived the multiplicity acquired by this disease as it was manipulated by doctors, patients, nurses and lab technicians, among other professionals. In this context, tuberculosis emerges as a product of the condensation of different practices, microscopes, slides, examinations, conversations and interpretations.

Understanding tuberculosis not only through symbols and interpretations, but also as a result of the coordination of different practices and materialities, allowed us to broaden the knowledge about this disease, to identify how it is performed and how its different versions coordinate. This gives rise to the possibility of detecting points of tension in this process that may prevent the treatment of the disease, as exemplified above. And, on the contrary, it shows how coordination processes can work and favor the diagnosis and treatment of tuberculosis.

We realize that reality does not precede the practices, but it is also enacted by them, recuperating the boundaries between the different sciences. When varied practices produce versions of the same object, the diversity between them - in terms of importance or precision - becomes a minor issue in the face of the collaboration between these agents in the formation of a single disease that includes all versions.

Perhaps one of the most important aspects of the use of praxiology in order to understand a disease as complex as tuberculosis is to avoid emphasizing the difference of meanings that the agents involved attribute to it; and at the same time to start appreciating the collaboration among them.

Authors' contributions

Isabela Pellacani Pereira das Posses conducted field research, designing and delineating the work, discussing the results, drafting the manuscript and approving the final version of the manuscript. Regina Matsue participated in the design and delineation of the work, critical revision of the content and approval of the final version of the manuscript. Pedro Paulo Gomes Pereira carried out design and work design, discussion of results, critical review of content and final approval of the manuscript.

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