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Social representations on the disclosure of the tuberculosis diagnosis and its relationship with the adherence to treatment

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Abstract

This regards an ongoing MSc Research that addresses the diagnosis exposure of tuberculosis as (a) an educational process aiming to build certain knowledge and to transform a given situation. From November 2010 to February 2011, 34 patients under treatment for tuberculosis and 39 health professional involved with the exposure of tuberculosis diagnosis (doctors, nurses and nursing assistants) were interviewed. The used instruments were semi-structured interviews aiming to raise social representations of both social realms (professionals and patients) about the way to communicate diagnosis and the adherence to treatment. As preliminary results, patients identified some discursive categories, which were important when thinking about a transformation process during the moment of the diagnosis exposure. Such transformation can facilitate adherence to treatment at this moment. These categories describe how the professional communicates the news, on the explanation given about what the disease consists (of) and the patient who does not understand (state of not understanding) the treatment process (by the patient). These are some of the categories that indicate the importance of undertaking a transforming diagnostic exposure, if targeted to change a reality.

Key-words: Tuberculosis; truth exposure; adherence to medication; social representations; discourse of the collective subject

Introduction

We may consider that tuberculosis has undergone three major social representations to date.

The first can be called "social representation of intellectual genius". This period is marked by the early eighteenth century until the mid-nineteenth century. Tuberculosis was characteristic of intellectual and artistic figures, endowed with sensibility; a romantic experience of the disease.

The tubercular of this era were portrayed as interesting people, because they affirmed themselves as powerful personalities through the disease, not just by intellectual production, but "through the narcissistic cultivation of testimony outside of their illness" (PORTO, 2007, p. 44).

In the second half of the nineteenth century, the investment of the bourgeoisie(ruling class of the capitalist mode of production) in spreading its precepts of strength, stamina, and physical agility (labor force) modifies the representation of the disease, which changes from its perception as something refined to a symptom of "social disorder". At this point, romantic exaltation is no longer appropriate, but the maintenance of productive bodies (fruit of the industrial revolution).

Due to ignorance of the causes and the ineffectiveness of treatment (which was only conquered almost in the middle of the twentieth century), horror of the disease spreads and transforms social behavior, which becomes a concern with the reorganization of society. The twentieth century marks a possible shift in the representation of the disease; it is no longer associated with elegance, nor simply isolated to the issue of a non-productive body. Now, the disease migrates to the poorer classes of the population, becoming synonymous to hunger and the consumption of alcoholic beverages.

Brazil is one of 22 countries prioritized by the World Health Organization (WHO), which together

represent 80% of the global bacterial load (BRAZIL, 2010). In 2007, Brazil reported 72,194 new cases, corresponding to an incidence rate of 38/100,000 inhabitants (BRAZIL, 2010). These indicators placed Brazil in the 19th worldwide position as to the number of cases, and at the 104th worldwide position in relation to incidence rate (WHO, 2009).

Each year 4,500 people in the country still die of tuberculosis, a curable and preventable disease. In 2008, tuberculosis was the 4th leading cause of death from infectious diseases (BRASIL, 2010).

A complete treatment, with healing and no recurrence of the disease, lasts, at least, six months. Health professionals should therefore promote appropriate treatment, avoiding the abandonment of medication before its completion (BRAZIL, 2002).

After the implementation of the short term scheme (6 months of treatment) in Brazil , in 1980 (before, the treatment lasted from 12 to 24 months), added to the free distribution of medicines (there was always free distribution of medication for tuberculosis, since the time of the sanatoriums), reduced rates of noncompliance with treatment were expected (BRAZIL, 2002). "This did not happen and it is a major obstacle to tuberculosis control because, apart from maintaining the sources of infection, many of these patients are resistant, disseminating bacilli that are resistant to major drugs among the population" (BRAZIL, 2002, p. 37).

The rate of cure and of the abandonment of tuberculosis treatment in São Paulo is still unsatisfactory in relation to the goals set by the World Health Organization (WHO). To control the disease, it is necessary to cure 85% of the cases and to have an abandonment rate for treatment below 5%.

In one historic series from São Paulo , during 1998 to 2008, the cure for new cases of tuberculosis, of every type, residing within the city, ranged from at least 62% (1998), to 73.7% (2007) at the most. On the other hand, treatment abandonment for the same period ranged from 11.1% (2004), at least, to 19.4% (1998), maximum (COVISA, 2009). That is, the city is far from achieving the goals set, requiring new strategies of approach.

Regarding the Supervision of Health Surveillance (Supervisão de Vigilância Sanitária - SUVIS) "Campo Limpo", empirical universe of the study, a cure for new cases of tuberculosis, of all types residing in the city, in 2008, was 83.2%, and noncompliance was 5.5% (COVISA, 2009).

The definition of adherence for long term therapy is the measure by which a person's behavior (whether taking the drug, following a diet, behavior change, etc…) corresponds with the recommendations agreed upon with health professionals (WHO, 2003).

But there is a difference between *adherence* and *compliance* .Adherence requires a patient's compliance with the recommendations given. Therefore, the recommendation is that patients should be active partners so that there is good communication between them and the health professionals (WHO, 2003).

Specifically in regards to tuberculosis, the definition of adherence can be understood as the extent to which the consumption of medication by the patient corresponds with the prescribed treatment (WHO, 2003). In this case, even when discussing long-term therapy, the dimension that extends beyond the taking of the drugs is rather tenuous.

Adherence to treatment can be measured in several ways, through the results of treatment (cured or not); through the cure rate of a service, for example, by counting the tablets to be taken and / or not taken by the patient; and others (WHO, 2003).

The point that separates the accession of abandonment may be given as the point between the therapeutic outcome desired and the undesired outcome because there is still no empirical reason to define the abandonment of the treatment of tuberculosis (WHO, 2003).

It is possible that before the current complex situation, where health problems can no longer be solved by specific measures, such as pure medication, without other intervention, it is necessary to adopt equally complex forms of action. Social and scientific practices should be extended, and break down barriers of disciplines and specializations, giving way to approaches that consider the consistency and longevity of the actions.

Meeting the needs of the people goes beyond the biological aspects of the same: this form of address, considering the patient within a life context, creates a space for dialogue between patient and health professional, a space that promotes the basis that determine the adherence to treatment (BERTOLOZZI, 1998).

Traditionally, the field of health / disease is linked to a conflict between sanitary logic - science and technology generating products and services - and the logic of common sense - which transfers management and control of the body to the specialist and the market (LEFÈVRE, F.;

LEFÈVRE, A., 2009).The speech of the health professional is considered an authoritative, legal speech, because it results from the scientific and technical field (LEFÈVRE, F.; LEFÈVRE, A., 2009). In contrast, the speech of the "average person" is unauthorized, illegal, since it comes from an area that is not valued, uneducated (LEFÈVRE, F.; LEFÈVRE, A., 2009).

Thus, the health professional and the patient become conflicting owners of the body, since the professional is the one with the power to drive the healing process and the patient is the one in which the health / disease process is occurring. It is forgotten that the patient is not only the owner of the body, but has freewill, free to collaborate, doubt, disagree, prevent, or disapprove.

The professional relationship between healthcare-patient becomes unbalanced because it seeks to "educate" the patient who is seen as a layman.

But this does not signify making the patient an expert on the subject; it simply implies making "significant" information available to that person so that he or she can make autonomous decisions.

However, to note what is meaningful to someone, there must be dialogue, not a doctrinal managing of the other person. It is about empowering people, which does not currently happen as health information is being used as mass advertising with "behavioral prescriptions", usually worded in the imperative: don't smoke, don't have sex without a condom, buckle up, don't stop treatment [...] " (LEFÈVRE, F.; LEFÈVRE, A., 2004, p.61).

This research adopts the diagnostic disclosure called "initial interview diagnosis" of tuberculosis as an educational process, as it deals with communication as a pathway to constructing a certain level of understanding. This is a significant moment in the overall narrative involving TB as it is the moment that reveals, to that person who placed their complaints in the hands of another, the mystery of the symptoms. It is a moment that differs from any other (an appointment, the first consultation, collection and examination, etc...), because that is where the "truth" appears, the truth of having a disease that can lead to death.

The simple transmission or delivery of information are actions that deny the other as a being of change in the world (Freire, 1982).In this study, the disclosure of diagnosis is understood as an educational process, in the sense that everyone involved in the action, especially the ill, are agents of transformation within the situation that presents itself.

"[...] is the act of knowing the one through which a subject, transformed into an object, patiently receives a content from another?" (FREIRE, 1982, p. 26).

When we do not consider the prior knowledge (culture, beliefs, knowledge) of the other person with whom we dialogue, an overlapping occurs of "another way of thinking, which implies another language, another structure, and another way of acting [...]"(FREIRE, 1982, p.31) causing "a defense reaction against the 'intruder' that threatens to disrupt their internal balance" (FREIRE, 1982, p. 31).

A great example of the importance of the communication for adherence to treatment was broached by Sa et al (2007), when describing four stories on the abandonment of tuberculosis treatment: a content analysis of the speeches reveals important data about the professional relationship of healthcare / patient. In one of the speeches collected, the participant reports not being informed about what the disease was, a disease he/she had no understanding of, so "it may be affirmed that, in many cases the patient abandons the treatment, because he/she was abandoned by the health service "(Sa et al, p. 717), leaving the same, represented by the fragile communication between professionals and patients.

Having lifted these comments, the present study, one of the requirements for obtaining the title of Master of Public Health from the Post-graduate Program for Public Health at the University of São Paulo (FSP-USP), developed with a grant from the Coordination for the Improvement of Higher Education Personnel (Coordenação de Aperfeiçoamento de Pessoal de Nível Superior - CAPES), has the following question as its research problem: How can the "initial diagnostic interview" - which is one of the many interactive moments that occur between the healthcare professional (s) and the patient - reflect the adherence or non-adherence to treatment, from the point of view of the healthcare professionals and from that of the patients?

The first theoretical basis chosen to support the research relates to method of data collection. We chose to raise the subjects' speeches through social representations, because they provide a position from which an individual or a group interprets situations. They are the benchmarks by which people communicate. A word, phrase, or a simple question are able to mobilize a social manifestation (SEMIM, 2001).According to this theory, we feel the need to be informed about the world around us, to adjust ourselves to it physically and intellectually, and to identify and solve problems. We share this world with others, and that is why the representations are of a social nature. The representations guide our interpretations of various aspects of reality, circulating

through speeches and conduct (JODELET, 2001).

The second basis, of methodological nature, concerns the organization of the speeches post collection. The method chosen was that of the Collective Subject Discourse (CSD). It is a method that seeks to transcend the line between quantitative research - traditionally "large and shallow" - and qualitative research - traditionally "small and deep" - toward an integration of both so as to better match the nature of events (LEFÈVRE, F.; LEFÈVRE, A., 2005), seeking to salvage "a way of thinking collectively" (LEFÈVRE, F.; LEFÈVRE, A., 2005, p. 18).

The goal is to add, for a set of semantic similarity, a set legend (individual statements of a similar meaning) in order to better represent the community in this study. They are interviews with open questions for the expression of social representations.

The last theoretical basis is related to the analysis of the collected speeches already organized into collective discourses through the DSC. The same are under review in regards to the communication mode of the diagnosis based on the six key ideas presented by the teacher Paulo Freire, as the six ideas necessary for the process of raising awareness. They are listed as follows:

> 1. All educational activities should be preceded by reflection on the man and his cultural milieu.
>
> 2. The more the subject reflects on his reality the more committed and prepared he/she will be to intervene in it.
>
> 3. The person should be recognized as an active participant and transforming force of reality. The person is not only within reality, but with the reality.
>
> 4. The mankind is the one who creates culture.
>
> 5. The mankind is a maker of history.
>
> 6. You need to prepare the people through authentic education, which frees and does not tame.

Paulo Freire discusses the critical and creative capacity of mankind, which is crossed by the process of "awareness". That is, a person cannot actively participate in the transformation of reality if he or she is not aware of reality and their capacity to transform it.

Having explained the benchmarks that guide the research, the following are the objectives of the same:

> 1. Raising the social representations about the "initial diagnostic interview" (specific moment when the patient receives the news that he/she has tuberculosis) as regards the form of communicating the diagnosis and as regards adherence to tuberculosis treatment, for health professionals who treat patients with tuberculosis and for tuberculosis patients.
>
> 2. To analyze the discursive content, as regards the mode of communication of the diagnosis and the relation this has with the adherence to treatment, based on six key ideas presented by Paulo Freire, as being the six ideas necessary to the awareness process.

The procedures for these objectives were an invitation for health professionals and patients to participate in research by submitting a Letter of Consent (IC), semi-structured and individual interviews recorded and transcribed (with three questions for health professionals and three questions for patients on the "initial diagnostic interview"), and analysis of the discursive content. The Statement of Approval from the Research Ethics Committee of the Municipal Health Secretariat of São Paulo (Comitê de Ética em Pesquisa da Secretaria Municipal de Saúde de São Paulo , CEP -SMS/SP) is no. 287/10, dated August 16, 2010 .

The researched social fields were:

> • Field 1: 39 health professionals involved with the "initial diagnostic interview" selected from among 22 health units, the SUVIS Campo Limpo, the Regional Health Coordination (Coordenadoria Regional de Saúde - CRS) in the South of São Paulo.
>
> • Field 2: 34 adult patients (18 years or older) undergoing tuberculosis treatment, of any type (pulmonary and / or any extra-pulmonary), in any form of treatment (supervised or self-administered), at any time within the allotted time for treatment (either scheme for 6 months / or further months for the other schemes) among the 22 health units in Field 1.

Prior to the final interviews, a pre-test of a semi-structured routine was carried out in two health

units of SUVIS Campo Limpo. SUVIS has a total of 24 basic health units (BHU), and 2 were used for the pre-test script, and 22 for research.

The pre-test identified difficulties on the part of patients and healthcare professionals in understanding the open questions. The main reason was the extensive use of questions. Very extensive questions disperse the attention of respondents. At the end of the question, respondents no longer knew what they were being asked in that statement. We decided to "mop up" the questions, making them more direct.

The pre-test is an important moment, not only to test the interview guide, but to visualize the operational level of data collection. Only by experience is it possible to measure the viability of the intended objective. Time management should be part of the methodology of any study.

As preliminary results, some discursive categories were identified, by patients, which were important to consider within the transformation process during the period of disclosure, a transformation that can facilitate the adhesion to treatment at this key moment.

Here are some discursive categories:

For the first question of the script that asked the patient to tell us how they received the news that he/she had tuberculosis:

- News of the patient's illness was given directly, without further explanation.

According to the third key idea given by Paulo Freire, when the subject is led to reflect on their reality and find that they are not in it, but with it, it places them in a situation of confrontation, leading them to respond to the challenge placed in their life. In this category, some patients expressed that there was nothing beyond the filing of the news, pushing them into the position of inanimate objects and liabilities.

For the second question that asks the patient to state what he/she believes can motivate a patient to adhere to treatment:

- Further explanation on what the disease entails.

Key idea number six argues that, through dialogue, the subject can be the creator of man himself, of his work. Communication enables a critical and creative experience.

The third question asks the patient to relate to situations that can lead to withdrawal from treatment at the time of diagnosis disclosure:

- Patients may drop out of treatment because they did not understand the explanation for the treatment.

The fourth principal idea is with respect to reflections on life context. A speech integrated into the context, the reality being lived, eventually leads to a reflection on said context and an answer the challenge.

These are some categories and some analysis on the same, indicating the importance of conducting a diagnostic disclosure that is transformational, if what one wishes is to change a reality.

Every encounter is a pedagogical encounter, especially between "different" people, where the opportunity for exchange is present. The meeting of the "initial interview diagnosis" for tuberculosis would not be different from this. It can be considered a good time to *start* making the necessary change, and in an enduring way.

The survey of social representations of the players involved at this point contributes to identifying the location of communication weaknesses between them.

Competing Interests

The authors declare that they have no competing interests.

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