



Social representations of tuberculosis*

Representações sociais sobre a tuberculose

Representaciones sociales sobre la tuberculosis

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ABSTRACT

Purpose: To identify social representations of tuberculosis among individuals with the disease who were receiving treatment at a specialized service in a municipal district of Santa Catarina, Brazil. **Methods:** The sample consisted of 25 individuals with Tuberculosis. Data were collected through semi-structured interviews. The theory of social representations guided the content analysis of the data. **Results:** The main theme was “living with tuberculosis is suffering.” This theme was supported by three sub-themes: (a) treatment of tuberculosis is difficult; (b) tuberculosis isolates people; and (c) tuberculosis changes an individual’s perception of himself or herself. The representations of tuberculosis were expressed as loss, sadness, dissatisfaction, and revolt. **Conclusion:** The representations of tuberculosis as a suffering condition indicate the need to develop support network for people with the disease and the need to work through prejudices, being afraid of the disease, and indifference to people with the disease.

Key Words: Tuberculosis; Social representations; Qualitative Research

RESUMO

Objetivo: Conhecer as representações sociais da tuberculose de pessoas acometidas pela doença e atendidas em um serviço de referência de um município de Santa Catarina/Brasil. **Métodos:** Os dados foram obtidos através de entrevistas semi-estruturadas realizadas com 25 pessoas de um serviço de referência. A análise foi efetuada sob a ótica da análise de conteúdo, tendo como referência a teoria das representações sociais. **Resultados:** A análise dos dados nos levou a compreender que há um tema central que expressa como representam a tuberculose: viver com tuberculose é sofrido, apoiado em três categorias: O tratamento é difícil, a tuberculose afasta as pessoas, a tuberculose muda a percepção de si. As representações sobre a tuberculose foram expressas num relato de perdas, de tristeza, de descontentamento e de revolta. **Conclusão:** As representações da tuberculose como sofrimento apontam a necessidade de promover a criação de uma rede de suporte às pessoas com tuberculose e de trabalhar preconceitos, medos e respeito às diferenças.

Descritores: Tuberculose; Problemas sociais; Pesquisa qualitativa

RESUMEN

Objetivo: Conocer las representaciones sociales de la tuberculosis de personas acometidas por la enfermedad y atendidas en un servicio de referencia de un municipio de Santa Catarina/Brasil. **Métodos:** Los datos fueron obtenidos a través de entrevistas semi-estructuradas realizadas con 25 personas de un servicio de referencia. El análisis fue efectuado bajo la óptica del análisis de contenido, teniendo como referencia la teoría de las representaciones sociales. **Resultados:** El análisis de los datos nos llevó a comprender que hay un tema central que expresa como representan la tuberculosis: vivir con tuberculosis es sufrir; este se apoya en tres categorías: el tratamiento es difícil, la tuberculosis aleja a las personas y la tuberculosis cambia la percepción de sí. Las representaciones sobre la tuberculosis fueron expresadas en relatos de pérdidas, de tristeza, de descontentamiento y de rebeldía. **Conclusión:** las representaciones de la tuberculosis como sufrimiento apuntan la necesidad de promover la creación de una red de soporte para las personas con tuberculosis y de trabajar prejuicios, miedos y respeto para las diferencias.

Palabras clave: Tuberculosis; Problemas sociales; Investigación cualitativa

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INTRODUCTION

There is an estimative that more than 50 million of the Brazilian people are infected by *Mycobacterium tuberculosis*. It is possible to calculate the emergence of 110,000 new cases of tuberculosis each year, and only around 80,000 cases will be notified. The number of deaths from tuberculosis in Brazil is over 6,000 per year. The cure rate of the treated cases is only 72%, when it should be at least 85%⁽¹⁾. Brazil occupies the 18th place among 22 countries responsible for 80% of all tuberculosis cases in the world⁽²⁾.

These numbers are alarming if we consider that tuberculosis is curable, and they show the need of reviewing some actions together with this population. We believe the investments related to the tuberculosis control have been important, however not enough, considering the development of the disease in Brazil. One of the main sources of this situation is the non-completion of the treatment regimen, with frequent dropouts and inadequate use of drugs possibly linked to the treatment side effects and its long-term effect; to the clinical improvement during the first months of treatment; to difficulties in attendance at health units; to the non-acceptance of the disease; and failures in the tuberculosis control program⁽³⁻⁴⁾.

Tuberculosis has been ambiguously represented in different periods of history. Until mid-twentieth century, when the effectiveness of chemotherapy for tuberculosis was not yet a reality, the disease used to generate a diversity of feelings about its overcoming and they were represented in several ways, both individual and collectively. As a mortal disease, tuberculosis was seen as an inevitable result of a life dedicated to overindulgence, therefore in disagreement with the socially acceptable standards, although having distinct contours depending on the time⁽⁵⁾.

In the twentieth century, with investments in public health policies, the representations of tuberculosis start a demystification process. The disease, no longer an expression of a morbid elegance (as the romantic sensibility and refined spirituality), takes up more dramatic contours because it features obvious symptoms of social poverty⁽⁵⁾.

Tuberculosis remains a disease shrouded in taboos and beliefs of a symbolic nature, surrounded by a strong stigma which has been evident since ancient times among the most different nations. Despite the scientific progress which has made available some efficient treatments, even currently, popular beliefs about tuberculosis seem to preserve lots of images that made it one of the most dreaded diseases of all times⁽⁶⁻⁷⁾. The disease's stigma lead people who contracted tuberculosis to suffer not only from its clinical manifestations, but also from prejudice, and from being rejected in their social relationship⁽⁸⁾.

The concept people have about tuberculosis etiology and infection is not restricted to the biomedical knowledge about the disease, but it includes a wide range of different understandings

and possibilities which are not recognized by the health service, but are social disease's constructions⁽⁹⁾.

Frequently, diseases such tuberculosis are in the imagination associated to traditional beliefs about the health moral nature, illness and human suffering. These diseases ultimately symbolize many types of anxiety people have, as is the case of the divine punishment. In their minds, these diseases are more than just a simple clinical condition; they became metaphors for daily life⁽⁷⁾.

We use as a theoretical reference in this study the theory of Social Representations of Serge Moscovici⁽¹⁰⁾. This theory connects people, symbols and behaviors that are derived from the experience of every human being and according to the ideology of the society they are part of.

With a view to deepen the knowledge about the social representations of tuberculosis and contributing to the development of new health care strategies retaining to the reality of these people, we developed the study which aimed to understand the tuberculosis social representations of people affected by the disease and seen in a reference institution from a city of Santa Catarina, Brazil.

METHODS

This is a qualitative study, carried out in a municipal reference institution in the control of tuberculosis.

For collecting data, all 43 program participants subscribed in the period settled were invited. They met the following criteria: to be adult (over 18 years old), to be under tuberculosis treatment, agree to participate in the study and have a good verbal communication. As a result, 25 people agreed to participate in the study.

Data were obtained through semi-structured interviews which were conducted by a guide person who had identification data and questions about the tuberculosis representation. Interviews were recorded and transcribed after respondents' formal authorization⁽¹¹⁾.

The analysis was performed and based on the thematic categorical content analysis, and, having as reference the Theory of Social Representations, the steps below have been followed:

- Preanalysis: includes the interviews transcription, a material reading for a first approximation to the general guidelines structure and discovery for analysis, also recording the message impressions. Summaries of each interview performed were prepared in this step, trying to capture the most general sense of the statements. The most representative elements considered were those that were repeated, where greater emphasis was given, and those that could express globally what people used to feel and think about their health condition. This analysis helped us to have a wider view of the speeches set.

- Material exploitation: the interviews were read several times

to grasp the elements presented in the speeches. The interviews coding was performed, in order to capture the elements which integrated representations. After this procedure, code reorganization was performed, establishing a concept that could cover elements and ideas grouped together and elaborating categories which converged on the central theme.

- Treatment results obtained and interpretation: data were discussed and interpreted in the light of the theoretical framework of social representations. In this stage, we try to catch the underlying content of what was being expressed in a process of grasping the meaning of study subjects' statements. The elements regarded as most representative were those which were repetitive, in which there was more emphasis, and those that could express globally what people used to feel and thought about their health conditions.

Subjects accepted to take part by giving their written consent, assuring that the ethical principles were observed. The research project was approved by the Research Ethics Committee, Universidade Federal de Santa Catarina under the number 235/05 and complying with Resolution # 196/96 of National Board of Health. Subjects' names that appear in speeches are fictitious.

RESULTS

Speeches analysis lead to the understanding that there is a central theme which expresses how people represent tuberculosis: Living with tuberculosis is very hard. This representation is based on three categories: Tuberculosis isolates people, treatment is difficult, and it changes individuals' perception about themselves.

Living with tuberculosis is very hard

Being affected by tuberculosis is perceived as a suffering due to social exclusion experienced by people, due to the challenges of the treatment, the fear of contagion, and the change in the perception of the body image. This leads to the understanding that the representations about tuberculosis are expressed as losses, sadness, discontentment, and revolt.

Suffering expressed by the members of the study has as reference the understanding that tuberculosis is not only a body's disease, but it has implications in different living areas, especially in social relationships. These relationships change, leading to isolation due to the prejudice they perceive from other people, and also by the prejudice against tuberculosis, leading them to feel "dirty" and a risk to the other people. Physical manifestations such as cough and weight loss, coupled with the perceived prejudice, contributes to change the image they have of themselves to ill and frail. In this sense, the experience of having tuberculosis leads to suffering, modifying the daily life, and the way people connect with themselves and with other people.

Tuberculosis isolates people

This category was built from two conceptions. The first one is that tuberculosis is a disease that is transmissible from one person to the other and however, the physical interaction space becomes a risk space. The second conception is related to the disease's stigma, which generates prejudice, connecting the disease to the lower social classes, to promiscuity, and to others exclusion social situations.

The disease's transmissibility is expressed in different ways and was present in the speech of all study members. Even those who knew they were not a transmissible agent any more, remained worried, showing that the representations they used to have about the disease did not change with the guidelines given by health care professionals.

"The mask is like this, I'm not sure, neither yes or no, what catches or don't. Until now nobody caught it, but who knows in the next few years... So the mask is a prevention to prevent people from getting affected by the disease."(Maria)

Fear of contamination makes people affected by tuberculosis feel excluded, or isolate themselves, in a type of reaction that, sometimes, is like anticipation: to isolate themselves before being isolated by other people.

They expressed fear of revealing the diagnostic and preferred to keep the disease in secret, as a consequence of the prejudice that there is. This situation lies in the fear of social judgment, i.e., in the fear of: humiliation, shame, as demonstrated by the following statement:

"I didn't tell it, because there are still people who avoid to be friends, you know. They don't look at you anymore to talk. They don't shake hands anymore..... at work they don't let me work. They can't accept me working there, because they are afraid of getting the disease." (Luís)

The prejudice also contributed to the isolation, even with close relationships, such as spouses and children. The prejudice with people affected by tuberculosis does not come only from the other people; it also comes from the person himself, based on their conceptions on the disease.

"tuberculosis is all bad, I lost my family, my girlfriend, my sisters don't talk to me anymore. My nephews don't visit me, don't hug me, don't kiss me". (Manoel)

"prejudice is a thing that put us down. Because if we are in some place talking, and the dude tells that he'd already had tuberculosis... Then people start to leave little by little, see... They don't have much respect with people's disease, do they? They are afraid of it. Perhaps if it hadn't happened to me.... I myself would be a bit retracted.. it depends on the person." (Antônio)

Tuberculosis treatment is hard

People include in this treatment a care which goes

beyond the doctor treatment such as: faith, protection against rain and damp and also spread this care to a healthy diet, the use of medications, and the periodical follow up by the health care services. This way of describing the treatment stresses the perception that the care with this disease includes the daily life, through attitudes which express previous experiences and knowledge.

The representation that tuberculosis has a hard treatment is due to the unpleasant sensations brought by drugs. There is a general recognition that the treatment is difficult and it requires self-commitment to get it done. When they report about the treatment, they build an image of being a winner for following the treatment, or if they cannot finish the treatment, they give different excuses. In these situations, they try to show that the treatment bring them more discomfort than the tuberculosis, expressing revolt. Generally they engage an internal battle, opposing the recognition of the need for further treatment, and the desire of not taking the drugs which bring them discomfort.

"well, this treatment now is good, but the previous one was very hard, it harmed me a lot. I had lots of headaches. I used to take the medicine at 8 o'clock and could wake up only at 5 p.m.". (Carlos)

"it's hard... The drug is very harmful ... Now, the stomach is a bit better, but I've suffered a lot...". (Cláudio)

"at the beginning I had a skin eruption, it was full of wrinkles, on my whole body, I was horrible..." (Marta)

"ah, that reddish thing sometimes popped on my body, you know ... Then I used to feel very weak. It was like measles. Then I didn't want to eat, I couldn't, I fainted..." (Zilma)

It is important to consider the beginning of treatment is also the time the disease is discovered. So, there is an overlap between receiving the news of having tuberculosis together with its entire burden together with prejudice, having to be under treatment with medicines that have lots of side effects, often stronger than the disease itself.

People associate the unpleasant manifestations of treatment performance to the reassurance that they are still ill. Some subjects, when symptoms are better, believe they are not ill anymore, and they stop taking the drugs. On the other hand, other subjects, when they perceive the drugs are having an effect on the symptoms, recognize its benefits and feel encouraged to continue with the treatment. These people reflect on their disease and include it in a historical and social context, thus having an awareness that they can interfere in their healing, preventing its recurrence, as it shows in the statement below:

"the treatment is very important, because we have a historical idea of the disease, that there was no treatment for it, right? It was a disease that really destroyed people. So that this won't happen again, people who are affected by this disease have to be treated. Otherwise, what happened before can happen again." (Luís)

Tuberculosis changes people's perception

People with tuberculosis change the way they see both their bodies and their social role. Prejudice and the physical manifestations such as cough, presence of sputum with blood, and weight loss contributed for this situation.

These see themselves as something that has become "dry", with almost no life. One of the interviewees described his self-image as a flower without petals, a tree without leaves and fruits, and an arrowed heart. These images were built from their experiences of significant weight loss, of feeling ill and social isolation, showing that the lack of vitality can change the self-image.

The lack of physical vigor and the impossibility of keeping their daily activities, including leisure and sexual life, contributes crucially for the change in the perception they have of themselves, they cease to be active and healthy people and start to perceive themselves as fragile and ill.

Death becomes a closer possibility. The disease's confirmation leads to the representation that tuberculosis can kill. Even though they know tuberculosis is curable, they think of a past situation of the disease and believe it can kill them⁽¹²⁾.

"I thought I was going to die, because I didn't have total knowledge (...) Then it was coming into the head the person used to die right there, spitting blood and it was incurable. That didn't exist anymore." (Emília)

DISCUSSION

As a representation of tuberculosis, suffering shows the disease's complexity and confirms that it can't be perceived only as a physical and/or psychological suffering, but that it is also an existential suffering for being related to the way people can perceive themselves in the world⁽¹³⁾.

Although it does not have a unique manifestation, suffering was somewhat present in all people who participated in the study and it is especially linked to the prejudice the disease still generates. This prejudice is related to the contagion idea, which is also demonstrated by another study which shows that individuals with pulmonary tuberculosis suffer with the disease, not only due to its clinical manifestations, but also to the possibility of experiencing prejudices and being rejected in their social relationships⁽⁸⁾.

The prejudice people can notice in other people is not a surprise, because they also have this same tuberculosis representation. It was found in a leprosy study⁽¹⁴⁾ that the self-stigmatization is connected to the "self"-identity, which is

experienced by individuals in a subjective manner. And this stigmatized individual living in the same society incorporates patterns, rules and identity models, leading to self-depreciation and to a certain self-contradiction or ambivalence.

Hiding the diagnosis of tuberculosis was a common strategy among people who participated in the study, in an attempt to be more accepted. This attitude is explained⁽¹⁵⁾ as a strategy to manipulate information. There is the concern of hiding the problem, mainly in relation to closer people who may have negative reactions. To discuss the dilemma that people with chronic diseases have to reveal the diagnosis, an author⁽¹⁶⁾ emphasizes that besides the risk of losing the self-acceptance and the autonomy, they can face the risk of being rejected and stigmatized because of the disease; of being unable to deal with others people reaction; and of losing the control of their emotions.

The representation of tuberculosis presentation as a disease with difficult treatment is in agreement with another study⁽⁸⁾. Authors reported that taking the medicine will depend on how people control or articulate their bodies and on their perception of a satisfactory body response to unpleasant sensations.

Tuberculosis expression in Brazil throughout the century is featured by such deep changes, that we could almost say that does not exist a single nosological form to describe the disease. If we analyze tuberculosis as its behavior in the community, it is currently different from what it was more than 50 years ago. Despite care efforts and the disease's control that have been carried out since the last century, there was a change in the profile of the affected people and the emergence of resistant bacteria, and the development of the multi-drug-resistant tuberculosis⁽¹⁷⁾. Additionally, tuberculosis became worse with the emergence of

the Tb/HIV co-infection, factors which contribute to make disease control even more difficult⁽¹⁷⁻¹⁸⁾.

Diagnosis present technological resources; treatment now involves different prescriptions; it changed the profile of affected people⁽¹⁹⁾. The contagion risk became also higher, the cure possibility is now effective, but, on the other hand, people are still feel discriminated by the prejudice which exists connected to the disease; they leave the treatment because they consider that it is usually worse than the disease itself; or because they can't understand the connection between the cure and remission of manifestations. Patients continue to have late diagnosis, with marked weight loss and cough with hemoptysis.

FINAL CONSIDERATIONS

We believe this work will help health care professionals understand tuberculosis is not only a physical disease; it becomes part of the lives of affected people. To understand this reality certainly will favor a more appropriate approach of care and treatment. Among the possible strategies, we consider important that health care professionals open spaces for discussion with these people, allowing them to express their fears and concerns, which may help overcome the prejudice related to the disease and find new ways to deal with the situation.

Another care strategy is to include the family and close people, so that they can better understand forms of transmission and can keep their relationships in a more confident manner. The study also shows the need for greater information about tuberculosis and how it is transmitted, as well as its onset, promoting prevention and earlier diagnosis and contributing to a new representation of this disease.

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