

Social representations of TB patients on treatment discontinuation

Representações sociais das pessoas com tuberculose sobre o abandono do tratamento
Representaciones sociales de las personas con tuberculosis en el abandono de tratamiento



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ABSTRACT

Objective: To understand the social representations of people with TB who discontinued treatment in a Program of Tuberculosis Control.

Method: a descriptive study of qualitative approach conducted in the city of Lima, Peru. Data were collected from October to November 2012, through semi-structured interviews with eight individuals and the method used was thematic content analysis.

Results: The categories led to the construction of the social representation that the disease and the treatment bring suffering. This representation influences non-adherence to treatment and may increase the rates of treatment discontinuation.

Conclusion: Educational strategies linked to social interaction processes, to subjectivity and to the patient context are needed to reduce the rates of discontinuation of tuberculosis treatment, relapses and multi-drug resistance. The evaluations point to new challenges that must be faced to achieve the Millennium Development Goals.

Keywords: Treatment refusal. Nursing. Tuberculosis. Millennium Development Goals.

RESUMO

Objetivo: Compreender as representações sociais das pessoas com tuberculose sobre o abandono do tratamento em um Programa de Controle da Tuberculose.

Método: Estudo descritivo, de abordagem qualitativa, realizado num município de Lima, Peru. Os dados foram coletados de outubro a novembro de 2012, através de entrevistas semiestruturadas, com oito pessoas, e analisados conforme a técnica de análise temática de conteúdo.

Resultados: As categorias levaram à construção da representação social de que a doença e o tratamento trazem sofrimento. Esta representação influencia na não adesão ao tratamento, podendo gerar um incremento de casos de abandono.

Conclusão: São necessárias estratégias educativas ligadas a processos de interação social, à subjetividade e ao contexto do paciente, direcionadas a diminuir o abandono do tratamento da tuberculose, as recidivas, a multirresistência. Novos desafios são apontados diante das avaliações frente ao alcance dos Objetivos de Desenvolvimento do Milênio.

Palavras-chave: Recusa do paciente ao tratamento. Enfermagem. Tuberculose. Objetivos de Desenvolvimento do Milênio.

RESUMEN

Objetivo: Comprender las representaciones sociales de las personas con TB en el abandono del tratamiento en un Programa de Control de la Tuberculosis.

Método: Estudio descriptivo de enfoque cualitativo, realizado en la ciudad de Lima, Perú. Los datos fueron recogidos entre octubre y noviembre de 2012, a través de entrevistas semiestruturadas con ocho personas y se analizó según la técnica de análisis de contenido temático.

Resultados: Las categorías llevaron a la construcción de la representación social de que la enfermedad y el tratamiento traen sufrimiento. Esta representación influye en la falta de adherencia al tratamiento y puede causar un aumento de los casos de abandono.

Conclusión: Son necesarias estrategias educativas vinculadas a procesos de interacción social la subjetividad y el contexto del paciente, dirigidos a reducir el abandono del tratamiento de la tuberculosis, las recaídas, la multirresistencia. Nuevos retos se señalan frente a la consecución de los Objetivos de Desarrollo del Milenio.

Palabras clave: Negativa del paciente al tratamiento. Enfermería. Tuberculosis. Objetivos de Desarrollo del Milenio.

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■ INTRODUCTION

Tuberculosis (TB) is a chronic infectious disease that remains a major public health concern in the 21st century, with high rates of treatment discontinuation and, consequently, the onset of new strains of the disease, e.g. multi drug-resistant TB (TB-MDR) and extremely drug-resistant TB (TB-XDR)⁽¹⁾.

In the third report "*Progresso e desafios na realização dos Objetivos de Desenvolvimento do Milênio* (ODM) (Progress and Challenges in the achievement of Millennium Development Goals (MDG) of Peru, in 2013, tuberculosis remained a major public health problem although prevalence rates had declined in the past two decades; however, more resistant and aggressive forms of tuberculosis are challenges to be overcome to control the epidemic⁽²⁾.

In Peru, TB-MDR, measured in sensitivity tests in 1997 and 2010, corresponded to 44 and 1,094 cases, respectively⁽³⁾, indicating a significant increase in the number of cases. In 2013, 31 thousand cases of sensitive TB, 1,260 cases of TB-MDR and 66 cases of TB-XDR were recorded. The cities with the highest incidence of the disease were **Madre de Dios, Callao, Ucayali, Tacna, Loreto** and **Lima**. In the capital, the highest number of TB cases were observed in the district of **San Juan de Lurigancho**, which comprises most of the population of Lima⁽⁴⁾.

The rates of treatment discontinuation in the period between 2008 and the first semester of 2010, expressed in percentages, are respectively 6.6; 6.3 and 5.8, showing a slight decrease, although these percentages are still high⁽³⁾. Several factors interfere in non-adherence to treatment, including socio-demographic factors: the number of male patients that discontinued treatment is higher than that of female patients; TB affects mainly the economically active population, generating more poverty and social exclusion; TB cases are also common among illiterates and individuals with elementary education. Another important factor that leads to treatment discontinuation is the use of drugs, especially alcohol and tobacco.

Discontinuation of TB treatment is very often associated with other chronic diseases, more specifically HIV infection. Other factors include previous experiences of treatment and lack of interaction and dialogue between health professionals and individuals with TB⁽⁵⁾. The magnitude of this issue in Peru stimulated the development of this study, not from a biological view, but rather from two perspectives: psychological and social. Given the lack of studies that address the views of TB patients who discontinue treatment in Peru, further research is therefore

required in this area. Thus, the issue is addressed within the context of social representations.

Social psychology promotes a dynamic approach of adherence to treatment, as it confers great importance to subjective assessment of the patient's attitude in the face of disease over time⁽⁶⁾.

Social representations are characterized by human interactions between individuals or between groups, who exchange meaningful information. Such information is under their control. The representations influence the individual's behavior. They are mentally created, so that the process itself penetrates, as the determining factor, into individual thought⁽⁷⁾.

Thus, knowledge of the social representations of patients who discontinued tuberculosis treatment by health professionals provide them with better conditions to make the most appropriate decisions and take the most efficient health care practices, thus contributing to the improvement of the epidemiological profile of tuberculosis. In view of the aforementioned, the following question is posed: what are the social representations of individuals with tuberculosis about treatment discontinuation in a Tuberculosis Control Program? The objective of this study, based on this questioning, is to understand the social representations of tuberculosis patients on treatment discontinuation in a Tuberculosis Control Program.

■ METHODOLOGY

Descriptive study with a qualitative approach⁽⁸⁾, in which the theory of social representations was used as reference⁽⁷⁾. The space defined for data collection was the city of Lima, Peru, where there is a high rate of discontinuation of tuberculosis treatment⁽⁹⁾.

The patients' medical records of individuals with tuberculosis were checked for compliance with the inclusion criteria. The following inclusion criteria were established: participation in the **Estratégia Sanitária Nacional de Prevenção e Controle da Tuberculose** – ESN-PCT (National Health Strategy for Prevention and Control of Tuberculosis); individuals of both genders, aged over 18 years; clinical and bacteriological diagnosis of tuberculosis; and confirmed treatment discontinuation. Eight participants were selected for the study. All of them discontinued tuberculosis treatment at some time during the treatment, according to the Tuberculosis Control Program. All participants were informed on the purposes of the study and signed the Free Informed Consent Form.

Data collection was performed in October and November 2012. In October, the executive management

of the Healthcare Network of the city of Lima granted official permission to conduct the study, which was disclosed to each of the health centers by the head nurse of the Network. Data collection included observations on the consultations/visits at ESN-PCTB, confirmation of the geographic zone and home addresses of the patients, the establishment of bonds between researchers and patients in TB treatment, and finally the interviews conducted in November. The semi-structured interviews were conducted in two steps. The first step addressed socio-demographic data of TB individuals, and the second step included guidance on issues related to treatment discontinuation. The interviews were guided by the following questions: How is your life without treatment? Tell me about it. What does it mean for you to discontinue treatment? Data were collected by researchers at the Health Centers and sometimes in the patients' homes, accompanied by a Nursing Technician, because some residences were located in hazardous areas. Each interview lasted in average one hour.

Data analysis was based on thematic content analysis⁽¹⁰⁾. The following steps were performed: pre-analysis, during which recordings of the interviews were transcribed verbatim and fluctuating reading after completion of transcriptions of the interviews. This step concerned representativeness, relevance of the contents and homogeneity of speeches. Coding, semantic classification, ranking and thematic reorganization followed.

The study observed the ethical principles of Resolution 466/12 of the National Health Council⁽¹¹⁾ whose project was approved by the Human Research Ethics Committee, of Universidade Federal de Santa Catarina, Brasil, under Protocol no.108.301, on September 26, 2012. The referred Protocol includes the formal permission to conduct the study of Peru's Ministry of Health. To ensure the anonymity of the participants, their statements were identified by letter P (person) followed by a number (P1 to P8) and age and gender.

■ RESULTS AND DISCUSSION

Socio-demographic and clinical profile

Regarding socio-demographic and clinical data, the age range of the participants was 19-49 years and most individuals were male. The educational level ranged from incomplete primary education to complete secondary education. Regarding marital status, one individual was married, three were single and four were separated because of the disease. Six participants were in

casual employment and two were unemployed. Some respondents reported living with other family members (parents, siblings, sister-in-law and in some cases, the mother), because half of them isolated themselves from their wives and children, and few had financial support from the family.

Six participants were successfully encouraged to get back to treatment by the researcher. Five of them had discontinued previous treatments twice, and one of them, three times. Analysis of the patients' records showed that six subjects had pulmonary presentation of TB-MDR and only two subjects had sensitive TB: one in the pulmonary form and the other a nodular form. Both resumed treatment under the National Strategy for Prevention and Control of Tuberculosis.

The socio-demographic profile of individuals who discontinued treatment identified in this study is consistent with the profile obtained in another study that showed the importance of these variables on the disease⁽⁵⁾. This study confirmed that the social conditions of individuals with TB have a strong influence on their decision to discontinue treatment. Thus, the patients have repeatedly discontinued treatment confirming that their decisions or behaviors are determined by their social context⁽⁷⁾.

Most patients had TB-MDR and had generally discontinued treatment twice or three times. It was found that community health workers administer the drugs in the homes of patients with multi-drug resistant TB, drug administration is not closely monitored, some patients are not given the number of doses required or self-administer their treatment. These agents are not paid by the State. These findings may indicate that poor treatments, especially those involving monitoring failures, favor the production of strains resistant to antituberculosis drugs⁽¹²⁾. Direct patient care by skilled health professionals may contribute to treatment adherence.

Three categories and one social representation emerged from the study: taking drugs is a bad experience because of side effects; treatment discontinuation/interruption causes/leads to death; and treatment discontinuation is caused by lack of social support, which leads to the social representation that disease and treatment bring suffering.

Taking medications is a bad experience because of the side effects

The construction of this category showed that almost all the individuals under TB treatment experienced side effects of the drugs, such as by pain, burning sensation, nau-

sea, vomiting and generalized pain throughout the body. Of these, most discontinued treatment. There were several statements like the one shown below:

[...] I could not take the medications because of my stomach; the pills made me nauseated. But I had to take them! Cursing! I was told to take the drugs: Take them! Take them! I had to take the pills slowly, with that sensation of burning in my stomach, terrible burning! So I did it. After taking them, I walked out with terrible stomach pains and flung myself into my bed (P2, 49 years old, male).

So, the side effects of TB treatment experienced by these individuals seem to be stronger than the symptoms of the disease, leading to treatment discontinuation. This fact corroborates the conclusion of other studies, as follows: this treatment can cause severe side effects, and is well known to cause damage to the gastrointestinal tract, which sometimes lead patients to interrupt treatment⁽¹³⁾. In multi-drug resistant tuberculosis, treatment is hindered by the high toxicity and poor efficacy of second-line drugs. Results suggest that optimizing the dosing of pyrazinamide, the injectables and isoniazid is a high priority in the treatment of multi-drug resistant tuberculosis⁽¹⁴⁾. According to this study, the side effects of second-line drugs lead to treatment discontinuation. Thus, studies on toxicodynamics are needed to reduce the toxic effects of medications and contribute to improved treatment adherence.

The statements also indicate that health professionals are only concerned with medication intake, without considering all the aspects involved in the treatment. It is inferred the lack of emotional support, important for patient adherence to treatment. This is more evident in the next statement in which the patient makes a comment about the attitude of the health professional:

[...] I discontinued treatment because of the nausea; the pills made me sick, I threw them up with the contents of my stomach. I was so nervous that I cried when I had to take the medications [...]. I had breakfast and then went to the Health Center, but was still feeling sick [...] I discontinued treatment in the second stage [...] I faced abuse. . It was horrible... because I refused to take the pills [...] (P3, 22 years old, female).

Treatment adherence is a multidimensional phenomenon that involves the interaction of several factors, especially the performance and responsibility of health-care professionals. It is known that a performance that

favors the development of ties between patients and health professionals contributes to reducing side effects⁽¹⁵⁾. Treatment adherence is not only about ensuring medication intake; understanding the individuals and their context, their lifestyles, family dynamics, beliefs, views and knowledge about the disease and treatment should be taken as a priority⁽¹³⁾. Conversations with patients about other issues besides tuberculosis and offering enough time to clarify doubts about the treatment are attitudes that contribute to the formation of ties, which may facilitate the identification of the patients' needs and the search for solutions⁽¹⁵⁾. Thus, the establishment of ties between healthcare professionals and patients, the understanding of subjective aspects of the patients are recommended to reduce side effects and improve patient adherence to treatment.

For other participants, the social representation of treatment discontinuation is expressed by the side effects associated to the length of treatment, as shown below:

[...] I discontinued treatment because it was too long [daily medications over a 9-month period], because I was afraid of the side effects felt in my previous experience. I discontinued treatment after five months (P8, 19 years old, female).

Individuals with TB are aware of the importance of treatment adherence to remain alive, get back to their families and fight stigma, but they may be tempted to discontinue treatment again because of the length of treatment, daily medications or due to the excessive number of pills to be taken. They feel deprived of their work and burdened by the high costs of some tests. Thus, a prolonged treatment and the excessive number of pills are the reasons to interrupt treatment. Treatment is discontinued because it is extremely unpleasant and restrictive⁽¹³⁾.

Treatment discontinuation causes/leads to death

Several individuals with TB use the image of death to represent treatment discontinuation. At first glance, it is paradoxical that someone associates (represents) treatment discontinuation with death and yet discontinues treatment. These representations of people with TB are based on cognitive contents of their lives, characterized by great difficulties to cope with illness in a social and economic structure of poverty that paralyzes them, because they do not know what to do, culminating in the repre-

sensation of death because of treatment discontinuation. The representations of death comprise various meanings for TB individuals, such as discrimination, psychological and physical pain, lack of resources and support and fear of death, motivating them to continue treatment and protect their families:

[...] discontinue treatment is to end life, is like a dying and repulsive dog. I have unpleasant symptoms and no one to help me; I had fever and was alone. I am only concerned with having something to eat. It is quite true that this disease causes me great suffering (P5, 22 years old, male).

[...] I interrupted treatment once, I am afraid of MDR and death (P4, 19 years old, male).

[...] My friend died, he discontinued TB treatment [...] This encouraged me to resume treatment (P7 24 years old, male).

[...] I think that treatment discontinuation is the beginning of death and death means leaving your children alone (P6 38 years old, female).

Individuals with TB compare themselves to dying animals that no longer deserve human compassion. These individuals have a significantly negative attitude towards themselves and the suffering caused by the disease. They are concerned with survival, knowing that treatment discontinuation may lead to death. They realize they are dying, so they need urgent care. These individuals are very lonely, which interferes with their behavior and the success of treatment. The representation of treatment discontinuation by death is consistent with a study that showed that discrimination by the hospital staff, professionals and nonprofessionals, is an important barrier to treatment adherence and something that causes pain and discomfort to TB patients⁽¹⁶⁾, demonstrating that the patient's context defines the psychological process⁽⁷⁾.

The need for humanized care emerges here. The bonds between patients and health professionals guide primary care, and thus these professionals must be able to listen to the patients' demands and provide them relief and support, to help them cope with their daily lives⁽¹⁷⁾. The **Directly Observed Treatment Short Course** (DOTS) consists in the surveillance by well-trained health professionals to ensure the patients take TB medication to prevent relapse or treatment discontinuation. The professionals that work with the DOTS not only need technical skills, competencies, knowl-

edge and responsibility, but also management and relationship capabilities, as well as an integrated and dynamic view of the world⁽¹⁷⁾. This must be reflected in their actions. The bonds may lead them to have social representations characterized by human interactions between individuals, groups, who share information and generate new meanings, which are under their control⁽⁷⁾.

Treatment discontinuation is caused by lack of social support

The contents of this representation indicate that the families of TB patients can get sick if they have contact with these patients. The fear of contamination experienced by the family members of TB patients leads to estrangement and isolation, as shown in the statement below:

[...] I live with my father. I am separated from my wife and my daughter [...] [because of TB] [...] My wife's family has also turned away from me; they disapprove of our relationship. (P2, 49 years old, male).

Lack of support from the wife and children can be the primary reason for TB patients discontinue treatment. Most participants of this study do not have a nuclear family, live in isolation and have little social support. Thus, fear of infection, self-discrimination and family discrimination can be perceived as factors that influence non-adherence to treatment, as family relationships provide social support, which is key to treatment adherence^(13,18).

However, according to the participants' statements, health professionals mitigated the isolation faced by individuals with TB (when the patients were admitted to the rehabilitation center), by being friendly to them and giving them advice and attention:

[...] the nursing technician, only her! She took the medications to the Rehabilitation Center [for drug addicts], and treated me well and gave me advice (P1, 22 years old, male).

This communication between health professionals and patients can facilitate treatment adherence. The bonds may contribute to the identification of needs and decision making⁽¹⁴⁾. However, discrimination is observed in social relationships. The individuals with TB identified discrimination by neighbors who refer to them as "consumptive":

[...] I don't talk with my neighbors [...] They say I am consumptive [...]. I don't care what they say, they discriminate

me. It is disgusting, they say. They turn away from me [...] well, everyone makes their own choices in life! [...] (P2, 49 years old, male).

People with TB hide their illness from their neighbors because of shame and fear of discrimination, and to avoid comments. Perhaps the real meaning of these statements is suggesting greater dissemination and knowledge of the paradigm of contamination to overcome the ingrained representations about transmissibility of the disease, since discrimination that occurs in the family and in relationships with neighbors and friends, may contribute to treatment discontinuation. Poor social support to the patients, both in the social and family contexts, is a limiting factor of DOTS actions⁽¹⁶⁾, which can lead to depression and treatment discontinuation.

Lack of knowledge on the duration of TB treatment, both in the first treatment and after discontinuation, which is a continuous treatment for 12 months, demonstrates that the support and guidance from health professionals are not sufficient:

[...] I thought I was healthy after two months of treatment. I did not believe that the treatment lasted one year. In fact, I did not know how many months should I take the medication [...] When I went to the Health Center, I never remembered to ask about the duration of the treatment, I felt healthy... The pills should not be taken for a long time, isn't it? (P8, 19 years old, female).

It can also be inferred that the DOTS strategy should be administered by expert health professionals, characterized by social commitment and humanization, and not by community agents. These values can contribute to reduce the rates of treatment discontinuation. It is well known that a successful drug therapy depends both in the quality of interaction between health professionals and patients⁽¹⁵⁾, and on education about the disease and treatment. Therefore, regarding tuberculosis in Peru, it is worth stressing the need to achieve Millennium Development Goal no 6, by promoting efficient interventions against this disease that had significantly grown until 2000⁽¹⁹⁾. Shared knowledge influence behaviors⁽⁷⁾.

Disease and treatment bring suffering

Suffering is explicitly or implicitly presented, in several ways, in the experiences of all the individuals who discontinue TB treatment, constituting a significant social representation. The behavior of the individuals who interrupt

TB treatment indicates that treatment causes suffering expressed in sadness, dissatisfaction and chronic pain. Some individuals are uncertain as to whether or not they will survive; others believe they will die because they discontinued treatment. The disease itself leads to other illnesses such as chronic depression and psychological pain caused by the physical condition.

Thus, this social representation – both the disease and treatment bring suffering – is supported in three categories: “taking medications is a bad experience because of the side effects”, “treatment discontinuation causes/leads to death”, “treatment discontinuation is caused by lack of social support”. In this study, discontinuation of TB treatment and the suffering of individuals with the disease are associated; hence, the experiences related to the disease and discontinuation of TB treatment are represented as suffering. This is consistent with a study that affirms that TB is represented by suffering⁽¹⁸⁾.

This social representation that disease and treatment bring suffering and, thus, lead to treatment discontinuation, can have a significant impact, not only on the particularities of those who live with the disease, but also on society, given the need for control and eradication of tuberculosis.

This investigation is inserted in the thesis about treatment discontinuation and its social representations for health professionals and individuals with tuberculosis⁽²⁰⁾.

■ **FINAL CONSIDERATIONS**

The present study aimed to understand the social representations of a group of individuals with TB on treatment discontinuation. Almost all the subjects had multi-drug resistant TB and had interrupted previous treatments, often because of the side effects of the medications.

Tuberculosis and treatment discontinuation were represented by the subjects as associated to suffering, characterized by fear of death and contamination, by the adverse effects of drugs and lack of social support.

In the representations of these individuals, side effects of the drugs, length of treatment and need to take too many pills led to treatment discontinuation. Such discontinuation brings the risk of death and the feeling of rejection. Discrimination by family, neighbors and health professionals is a limiting aspect for adherence to treatment by TB patients. Suffering is represented by the experiences during TB treatment and, during discontinuation of TB treatment, by the anxiety to meet their basic needs, the inability to work, symptoms associated to side effects and social discrimination.

Solidarity and social commitment are essential in the interventions aimed to obtain greater scientific knowledge on the illness and its treatment, in order to disseminate information that reduce the prejudices and discrimination related to living with TB.

The establishment of ties between health professionals and TB patients, with increased monitoring of these individuals, may contribute to improve drug tolerance. Special care should be given to educational interventions focused on the patients' social network (family, friends and neighbors), to improve treatment adherence when the subjects face the suffering caused by the illness. Social interaction during TB treatment between patients and nurses and between families and nurses generates reflections that enhance the care provided by the professionals with a positive impact on the patient's attitude towards treatment.

The DOTS strategy should be directly implemented by healthcare professionals, since the care to TB patients is more complex than that of other chronic diseases. The solidarity of health professionals, their commitment with TB patients and their professionalism will make it possible for these patients to overcome disease and treatment. Thus, it is suggested that, at the end of the first stage of the treatment, the professionals responsible for the implementation of the DOTS strategy, establish stronger ties with the patients and reinforce the need for total adherence to treatment until its completion, even after TB symptoms and signs disappear. It is believed that this can be the critical point between treatment adherence until completion of the therapy and consequent cure, and discontinuation that leads to unsuccessful treatment.

According to the theory of social representations, the social representation that disease and treatment bring suffering may increase the rate of treatment discontinuation.

This study may contribute to the development of a model of education related to the care provided to individuals with TB, under a psychosocial approach.

This model of education primarily suggests assessment of patients' social representations of treatment discontinuation in order to understand their logic and expectations. The interventions of the model can be based on the guidelines for the cognitive development of self-care, whose contents are focused not only on illness and treatment-related issues, but also on subjective aspects, ties and the sociocultural context of patients, allowing the formation of representations that have a positive impact on their behaviors.

This study is a contribution of nursing to the Millennium Development Goals, MDG 6, regarding tuberculosis,

considering the need for psychosocial interventions aimed to reduce discontinuation of TB treatment, relapses, TB-MDR and TB-XDR, and, consequently, its control.

A replication study is recommended, with repetition of the interviews with participants in order to validate the categories and social representations.

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