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RELATIONSHIP BETWEEN THE SOCIAL REPRESENTATIONS OF HEALTH PROFESSIONALS AND PEOPLE WITH TUBERCULOSIS AND TREATMENT ABANDONMENT

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ABSTRACT

Objective: to relate the social representations of health professionals and people with tuberculosis with treatment abandonment.

Method: a descriptive and exploratory study with qualitative approach. Twelve health professionals and eight patients participated from Health Centers in Lima, Peru. Data were collected, between June and July 2012, through semi-structured interviews, analyzed according to content analysis technique.

Results: similar content emerged from the analysis of the categories representations of both actors. They present similar aspects such as the treatment of tuberculosis generates suffering, tuberculosis is contagious and causes distancing and isolation, and the lack of knowledge generates treatment abandonment. These representations interfere with the conduct of care and adherence of tuberculosis treatment.

Conclusion: there is need for education strategies in a psychosocial approach, considering the multidimensionality of treatment adherence, contributing to the reduction of treatment abandonment rates and the tuberculosis transmission chain.

DESCRITOPRS: Treatment refusal. Nursing. Tuberculosis.

A RELAÇÃO DAS REPRESENTAÇÕES SOCIAIS DOS PROFISSIONAIS DA SAÚDE E DAS PESSOAS COM TUBERCULOSE COM O ABANDONO DO TRATAMENTO

RESUMO

Objetivo: relacionar as representações sociais dos profissionais de saúde e das pessoas com tuberculose com o abandono de tratamento.

Método: estudo exploratório-descritivo com abordagem qualitativa. Participaram 12 profissionais de saúde e oito pacientes de centros de saúde de Lima, Peru. Os dados foram coletados, entre junho e julho de 2012, mediante entrevistas semiestruturadas e analisados conforme a técnica de análise de conteúdo.

Resultados: da análise das categorias, emergiram representações de ambos os atores. Elas apresentam aspectos semelhantes, tais como: o tratamento da tuberculose gera sofrimento; a tuberculose é contagiosa e afasta as pessoas; a falta de conhecimento gera abandono de tratamento. Essas representações interferem no comportamento relacionado ao cuidado e à adesão ao tratamento da tuberculose.

Conclusão: há necessidade de desenvolver estratégias de educação psicossocial, considerando a multidimensionalidade da adesão ao tratamento, para a diminuição das taxas de abandono e da cadeia de transmissão da tuberculose.

DESCRIPTORIOS: Recusa do paciente ao tratamento. Enfermagem. Tuberculose.

RELACIÓN ENTRE LAS REPRESENTACIONES SOCIALES DE PROFESIONALES DE LA SALUD Y DE LAS PERSONAS CON TUBERCULOSIS EN EL ABANDONO DE TRATAMIENTO

RESUMEN

Objetivo: relacionar las representaciones sociales de los profesionales de la salud y las personas con tuberculosis en el abandono del tratamiento.

Método: estudio descriptivo, exploratorio y cualitativo. Participaron doce profesionales de la salud y ocho pacientes de centros de salud de Lima, Perú. Los datos fueron recolectados, entre junio y julio de 2012, mediante entrevistas semiestructuradas, y analizadas de acuerdo con la técnica de análisis de contenido.

Resultados: surgió representaciones de ambos actores que muestran contenidos similares, siendo la más importante: la falta de conocimiento genera el abandono del tratamiento. Esas representaciones interfieren en los comportamientos del cuidado y la adhesión del tratamiento de la tuberculosis.

Conclusión: existe la necesidad de estrategias de educación psicosocial, teniendo en cuenta la multidimensionalidad de la adherencia al tratamiento, que reduciría las tasas de abandono y la cadena de transmisión de la tuberculosis.

DESCRIPTORES: Negativa del paciente al tratamiento. Enfermería. Tuberculosis.

INTRODUCTION

Tuberculosis (TB) continues to be one of the deadliest communicable diseases worldwide.¹ In 2013, of the five South American countries, Peru reached incidences of 38,000 tuberculosis cases, representing 44% of cases in the Sub- Andean region.² The rates for the same year are 101.90 for morbidity, 55.30 for positive pulmonary tuberculosis sputum smear and 3.80 for mortality, per 100,000 inhabitants. One of the most important problems with tuberculosis is the high percentages of treatment abandonment, as identified in the cohort study on patient adherence to initial treatment in 2010 and 2011, which revealed an abandonment rate of 6.0% and 7.0%, respectively.³

People with tuberculosis who do not complete treatment remain ill and remain a source of contagion for the family and the population. In addition, abandonment leads to drug resistance and relapse of the disease.⁴ Treatment of multidrug-resistant tuberculosis is toxic, expensive, time-consuming and generally ineffective.⁵ In addition, it is difficult for patients to complete.⁶ Treatment is very varied and the risk of abandoning tuberculosis treatment is high at the end of the first month and beginning of the second, which corresponds to the phase in which the patients are asymptomatic, with good physical appearance and good general condition. This leads them to believe that they are free of the disease, and, as a consequence, they stop treatment.⁷

Due to the magnitude of this problem, it is important to characterize the treatment abandonment from a subjective and social perspective, from people with tuberculosis and health professionals in a public program. In Peru, research that addresses the social representations of tuberculosis treatment abandonment, both from the point of view

of people with TB and the perspective of health professionals, in their socio-cultural context is unknown. The understanding of the differences and similarities of their points of view may strengthen the care behaviors in the solution to the problems of treatment abandonment. Thus, the Theory of Social Representations was chosen as theoretical foundation of this study.

The representations, as a phenomenon, contain informative, cognitive, ideological and normative elements, which consist of beliefs and values, attitudes, opinions and images. These elements are organized under the guise of knowledge which says something about the state of reality. It is this significant totality that, in relation to action, is at the center of scientific inquiry. The task of describing, analyzing and explaining it in its dimensions, forms, processes and functions are attributed to this investigation.⁸

Research on the representations in the treatment of chronic diseases clarifies the different points of view of patients and health professionals, facing a problem of subjective importance. The opinions and attitudes that form common sense contribute to explain and understand the logic, the expectations and the foundations of the construction of the representations of the actors that come into interaction in this context.⁹

In this sense, the social representations of treatment abandonment of tuberculosis could allow the health professional to make decisions and actions of care which are more consistent with the understanding of the representations of the patients and, thus, contribute to the improvement of the epidemiological profile. From these situations, we aimed to relate the representations of health professionals and the social representations of people with tuberculosis with treat-

ment abandonment, in a National Sanitary Strategy for Tuberculosis Prevention and Control in Lima, Peru.

METHOD

This is a research with a qualitative, exploratory-descriptive approach,¹⁰ performed in four Health Centers (CSs) in the district of San Juan de Lurigancho, in Lima, capital of Peru. In this district, there is a concentration of the largest number of tuberculosis cases and the largest number of people at the national level who have abandoned treatment.

Data collection from health professionals occurred between June and July 2012, and with people with tuberculosis between October and November 2012. Data collection was performed for both groups through a semi-structured interview that included two stages. The first addressed the sociodemographic data of people with tuberculosis, and the second contained a guide relating to the issues of treatment abandonment.

Twenty subjects participated, of which 12 were health professionals and eight were people with tuberculosis. Of the professionals, four are doctors, three are nurses and five are nursing technicians, who are responsible for administering medication to people with TB at the Health Center. All of them are from the National Sanitary Strategy for the Prevention and Control of Tuberculosis (ESN- PCT), with ages ranging from 25 to 60 years and working there between a minimum of six months and a maximum of four years. The age group of people with tuberculosis who participated ranged from 19 to 49 years, five of them were male. Schooling ranged from incomplete elementary school to complete middle school. Most reported doing casual work, and others reported being unemployed. They also affirmed that they lived in precarious housing and had limited family financial support.

The professionals were invited to participate in the research after observing the two inclusion criteria: work directly in the Tuberculosis Control Program and to be working in the Program for at least six months. The eight people with tuberculosis were invited to participate in the research after conferring the inclusion criteria: to be linked to the ESN-PCT; people of both sexes; And be over 18 years of age and have a diagnosis of tuberculosis and have abandoned the confirmed treatment, i.e., not having attended the health unit to take the medication for more than 30 consecutive days.

Data analysis was guided by content analysis of thematic categorical type.¹¹ The following steps

were performed: pre-analysis, in which the recorded audio statements were transcribed in full. At that stage, it was a question of guaranteeing the representativeness, the relevance of the contents and the homogeneity of the speeches. The coding, semantic classification, hierarchization and thematic reorganization were continued, and in the case of health professionals generating the social representation on treatment abandonment, anchored in three broad categories. In the case of the patients, it was observed that the construction of the social representation that the disease and the treatment causes suffering based in the three categories. From the analysis of these two groups of categories, three social representations emerged.

The research project was approved by the Research Ethics Committee involving Human Subjects in the Federal University of Santa Catarina, under Protocol n. 108.301, registration 02961812.0.0000.0121, approved on 06/29/2012, and followed all the requirements regarding ethics in research with human beings. Consent was formalized by signing the Informed Consent Form (TCLE), ensuring respect, confidentiality and freedom of participation. To maintain the anonymity of the participants, they were identified in the text as follows: in the case of professionals, by the letter E and in the case of people with tuberculosis, by the letter P, followed by a sequential number from the interview, as well as by age and sex, in both actors.

RESULTS AND DISCUSSION

The results are presented, comparing the convergences and divergences of the contents of the speeches of health professionals and people with TB regarding treatment abandonment.

Medications and their effects lead to treatment abandonment

In the perception of the majority of professionals and people with TB, the adverse effects are related to the treatment abandonment. The content of the speeches of both groups, in relation to the treatment, is expressed in a similar way, but leads to different actions. These conflicting actions, for contextualized interventions and psychosocial development of relationships between people, impede reciprocal recognition among actors and are one of the critical aspects in the care and treatment of diseases.¹² For health professionals, the side effects of medications lead to the treatment abandonment. They highlight the objective aspects,

as they know the medicine, their effects and the patients' reactions, as can be exemplified in the following speech: [...] *more than half of the patients leave because they have side effects; Ethionamide causes side effects; it causes headache, nausea, vomiting and jaundice [...]* (E1, 26 years, male).

For people with TB, taking medication is a bad experience due to its side effects. The most common side effects experienced by the people were: hearing loss, dizziness, severe headache, nausea, gastritis, an at the moment of taking medication - despair and feeling bad, strong burning in the stomach, burning throughout the body, general malaise and desire to die while looking at the amount of pills. Thus, these people exclusively consider the subjective aspects, the experienced, what they feel, the reaction of the organism through signs symptoms and which is sometimes stronger than the disease at the time of the presentation of the side effects. There is much suffering present; an experience that leads patients to abandon treatment: [...] *I abandoned the treatment because of the nausea. The pills made me sick, vomiting them along with the food. I took the drugs, I cried, [...] ate breakfast and then went to the Health Center, even when I was vomiting, [...] I left in the second stage* [P3, 19 years, female).

There is similarity in the speech content of both groups of participants, but different behaviors are observed in treatment-related care. Antimicrobial drugs have adverse effects such as: gastrointestinal (nausea, vomiting, abdominal pain), hepatitis, rash and skin reactions, peripheral neuropathy, arthralgia, lethargy, drowsiness, hypersensitivity reactions, anemia, among others.¹³ We must know them well so as to identify them and act promptly. It is also important to adopt specific care in the event of adverse effects: confirm the dose of the drugs used; exclude other causes for the presented signs and symptoms; estimate the severity of the adverse effects; suspend the drugs responsible for the adverse symptoms, and eventually reintroduce the drugs gradually, according to the resolution in the chart.¹³

It should be emphasized that in Peru, the nurse's responsibilities are education, treatment control, early detection of side effects, monitoring of the person with TB and their contact with the Directly Observed Treatment, Short Course (DOTS). Drug administration is supervised in 100% of TB cases. It should be noted that treatment adherence depends to a great extent on the relationship between the person with tuberculosis, nursing and the health establishment.¹⁴ However, the treatment directly observed in the Health Centers is performed

by the nursing technician, and in the homes of people with TB, the unpaid health promoter is the one who immediately detects side effects and monitors treatment in these people. Thus, it is inferred that the harmonic and simultaneous action of the person with TB and of the nursing professionals can contribute to the decrease of the side effects of the medicines, i.e, this understanding and the relationship that is established between the health professional and the person with tuberculosis can improve treatment adherence.

It can be concluded that taking medication is an experience that causes side effects, requiring special attention from professionals and giving guidance to people regarding its control. Thus, the treatment of tuberculosis causes suffering.

Social discrimination causes treatment abandonment

Next, the thought logic of the professionals and of the people with TB regarding discrimination by family, neighbors and health professionals are compared.

The contents of the health professionals' speeches and people with TB regarding social discrimination are similar, since both point to the isolation and withdrawal of family, friends and professionals. For professionals, 'people with TB are discriminated against', because 'TB is contagious and causes fear', which translates into the isolation and separation of the person's personal utensils from the family nucleus, generating depression and unwillingness to continue with the treatment. This can be observed in the lines: [...] *their dishes and spoons are separated, including their bed, confining them. They do not feel like continuing treatment [...]* (E1, 26 years old, male); [...] *there are professionals and also nursing technicians who are afraid of the patient's illness. The faster you discharge the patient, the less you contaminate yourself, the air is in the room* [Mycobacterium tuberculosis] [...]. *They are working within this environment [...]* [health professionals]. *The only thing you can do is stay one and a half a meter away from the patient* (E6, 57 years old, male).

The individual feels isolated and points out that discrimination and self-incrimination as responsible for non-adherence to treatment. Family relationships provide social support, which is fundamental to adherence to treatment.¹⁵ It infers the unknown and the need to think about educational interventions with the family and the person with TB, especially on the paradigm of contagion and

prevention in the home, in order for professionals and patients to have the family's contribution to treatment adherence.

Health professionals and people with TB have identified self-discrimination and discrimination by neighbors, showing similar content. According to professionals, people are isolated and do not like their families and neighbors to know their diagnosis because they feel ashamed. Thus, there is discrimination and self-discrimination in the perception of these professionals. According to people with TB, the representation is also of discrimination and self-discrimination, translated into social isolation and the recognition of the representation which the neighbors do: [...] *I do not talk to my neighbors ... they say that I am a full of Tuberculous [...]. 'How disgusting,' they say. They isolate me [...]* (P2, 49 years old, male).

Representations are imposed on the group and are the product of a sequence of elaborations and changes that occur in the course of time.¹⁶ Self-discrimination may limit the treatment advancement. Social, family and patient stigma are limiting factors in the search for timely medical care and treatment actions.¹⁷

These representations suggest the dissemination of prevention measures by the mass media, based on studies of the subjectivity and socio-cultural context of people with TB, to overcome the challenge of the rooted representations of the disease, especially in the period of transmissibility, because discrimination present in relationships with neighbors and in families contributes to treatment abandonment. Insufficient social support for TB patients living in the social, family or community environment seems to negatively affect adherence and may lead to depression and hopelessness.¹⁸

This discrimination behavior shows the lack of knowledge about the multidimensional phenomenon of adherence to achieve continuity and success in treatment, such as the patient's reception, bonding and education. The bond includes a person-professional relationship, based on support, listening, narration of facts and stimulation of narration.¹⁹ Discrimination based on the fear of contamination may lead to non-adherence to treatment.

Adherence is a dynamic and complex phenomenon, with a wide range of factors influencing treatment adherence behavior. These factors are: 1) Structural factors (poverty and gender discrimination); 2) Social context factors (family, community and household influences); 3) Health services factors (such as the organization of treatment and care); and 4) Personal factors (knowledge, attitudes and beliefs

about the treatment of tuberculosis and the disease, and the financial burden of treatment).^{4,7,18} It should be remembered that education about the disease and its treatment is a fundamental part of treatment adherence.²⁰⁻²¹ Adherence is a result of exposure to situations of learning and coping of the individuals' situations in relation to disease conditions.²²

Finally, in this category of treatment abandonment due to discrimination, the speeches of health professionals and people with TB may represent that tuberculosis is contagious and distances people.

Lack of information leads to abandonment

There are similarities in the representations of both groups regarding the lack of information about treatment. The representation of people with TB, is that professionals do not inform them about the therapy, this is evidenced by the following statements: [...] *I asked about the pills, I asked them if they were vitamins or something, but they did not say anything! They just said, 'These pills are for the treatment of your lungs,' but they did not say, 'These pills are for this' [action of therapy] ... I never got lectures, I never received anything ...* (P7, 20 years old, male); [...] *Ignorance about TB is a cause for abandonment [...]* (E1, 26 years old, male).

Thus, there is a need for the appropriation of new scientific knowledge for the people with TB, both regarding the disease and the treatment of tuberculosis, in an attempt to modify the representations and actions of abandonment. The fear of transmission of the disease in the professionals is inferred. Isolation, poor education and a weak link between the person and the health professionals during the therapeutic treatment process are important aspects for the life of people with TB, generating behaviors which lead to treatment abandonment. Many factors associated with cessation of TB treatment reflect how professionals act and, in many cases, patients abandon treatment because they have been abandoned by the health service.⁷

According to health professionals, people with TB have no information about the disease and treatment, leading them to think that when they are well they do not need treatment. This is one of the causes of treatment abandonment, as observed in the speeches: [...] *they must understand that the disappearance of symptoms does not mean they are cured [...]* (E6, 57 years, male); and [...] *in most patients, the symptoms disappear in two months. The patient believes that they only have to do the treatment until then [...]* (E11, 62 years, female).

People with TB believe that they are healthy after two months of treatment, due to the improvement of the symptoms, that is, before finishing. They end up deciding that they no longer need treatment, and thus abandon treatment, possibly leading to resistant multidrug TB (MDR-TB), with its associated death-risk consequences: [...] *I thought I was healthy, almost two months of treatment ... and did not believe that the treatment was for one year [...]* (P3, 19 years, female); and [...] *they had been treating me for two months. They [health professionals] told me: 'you're recovering well'... they gave me a document for the CS there [an x-ray request]... so I said, I'm fine! I am recovered [...]* (P2, 49 years old, male).

The contents of the speeches are similar, but do not lead the actors to similar care behaviors, which lead to adherence and treatment continuity. According to the speeches of the professionals, people with TB decide to abandon the treatment because they do not know the necessary amount of time, treatment continuity and the reasons for the disappearance of the signs and symptoms. Thus, patient care must respond to the patient's expression of thinking and feeling in order to plan a personalized and adherent intervention to their reality, articulated with the interventions in the collective, aiming at the construction and reconstruction of the representations in this theme.²³ On the other hand, practitioners reinforce that people with TB have to take responsibility for their treatment. Thus, people with TB and professionals must share the responsibility for treatment, and it is important that professionals favor the bond between the actors.

Thus, an important representation is that lack of knowledge leads to treatment abandonment, either through discrimination and social isolation or lack of knowledge about care and treatment follow-up. The representations are "theories, collective *sui generis* sciences, intended for the elaboration and interpretation of the real".^{24:50} They are designed to restore a person's balance, which has been lost because of the presence of scientific knowledge in everyday life.²⁴

It is extremely important to know the awareness of the representation of health professionals and people with TB, as well as their meanings, to establish interventions. The representations can be intervened to change their contents, so that success in tuberculosis treatment can be achieved. Interventions based on a psychosocial perspective attest to changes in attitudes towards disease and treatment, and patients learn to deal with biological, medical, psychological and social difficulties.⁹

These representations are constructed in different contexts: in the consensual universe and in the objective universe. In the consensual, it is the everyday knowledge, in which the representations of the people with tuberculosis are constructed. In the objective universe, society is seen as a system with different roles and classes, whose individuals are not equal. The level of acquired qualification determines the degree of participation.⁶ Science is the mode of knowledge that corresponds to this universe in which truth and empirical evidence are sought. Scientific knowledge produces these representations, which are the representations of health professionals and people with TB that reveal the subjectivity of the actors. Subjectivity is a value that has been denied throughout history; its recuperation seeks to include it in health practices as a technological innovation that, in turn, protects the human meaning.

CONCLUSION

The contents of the social representations of health professionals are directly related to the representations of people with tuberculosis, regarding the abandonment of tuberculosis treatment in their life contexts. However, the contexts in which these representations are constructed are distinct. Health professionals have the scientific knowledge constructed in the objective universe, while people with tuberculosis construct their representations in daily life. However, both groups represented that the treatment of tuberculosis generates suffering, that tuberculosis is contagious and distances people and that the lack of knowledge generates treatment abandonment. The results of these representations among health professionals and people with tuberculosis can lead to different behaviors with regard to care, contributing to treatment abandonment.

Thus, there is a need for educational interventions based on a psychosocial approach, considering the multidimensionality of treatment adherence, the best measures of biosafety, social commitment and humanity that contribute to the reduction of abandonment rates, cutting the transmission chain of the different types of tuberculosis. We must, for example, reflect on the need to see the person with TB during the DOTS strategy, not only from a biological point of view, but also from a psychological and social perspective.

Thus, it is necessary to consider and respect the needs, feelings, knowledge and beliefs regarding the disease and the treatment itself; their ways of life and their family dynamics. It is also important

to reflect on all the dimensions that involve the multidimensional phenomenon of treatment adherence, and the link between the professionals and the person during therapy education about and its efficacy, and taking into account the needs of the person is paramount. One of the main difficulties resulting from treatment abandonment may be related to these gaps in care.

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