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# Social representations of tuberculosis by people with the disease

Representações sociais da tuberculose por pessoas com a doença Representaciones sociales de tuberculosis por personas con la enfermedad

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### **ABSTRACT**

**Objective:** To understand the social representations of people with tuberculosis about the disease and its implications for following treatment.

**Method:** A descriptive, qualitative study based on the Theory of Social Representations. It was conducted in a municipal health unit in the city of Belém. The participants were people diagnosed with tuberculosis and undergoing directly observed treatment, with the sample size defined by the data saturation technique. Data collection was done through semi-structured interviews. For data analysis it was used thematic content analysis.

**Results:** The records converged into three categories: Representations of tuberculosis and its impacts on the diagnosis; The faces of treatment: challenges facing follow-up and hope: and Constructions of living with the disease in family and society.

**Final considerations:** Living with the disease transforms everyday life and relationships. Discrimination and prejudice denote the need to reconfigure such representations for patients to be embraced.

**Descriptors:** Nursing. Nursing care. Tuberculosis. Social representation.

#### DECIIMO

**Objetivo:** Compreender as representações sociais de pessoas com tuberculose sobre a doença e implicações no tratamento.

**Método:** Estudo descritivo, de abordagem qualitativa, com base na Teoria das Representações Sociais. Realizado em uma unidade municipal de saúde no município de Belém. Os participantes foram pessoas com diagnóstico de tuberculose e em tratamento diretamente observado, cujo quantitativo foi definido pela *técnica da saturação de dados*. A coleta de dados foi realizada por meio de entrevista semiestruturada. Para análise dos dados utilizou-se a análise temática de conteúdo.

**Resultados:** Os registros convergiram em três categorias: Representações da tuberculose e seus impactos frente ao diagnóstico; as faces do tratamento: desafios frente ao sequimento e esperança; e Construções do conviver com a doença em família e sociedade.

**Considerações finais:** O conviver com a doença transforma o cotidiano e as relações. A discriminação e preconceito denotam a necessidade de reconfigurar tais representações, para o doente ser acolhido.

**Descritores:** Enfermagem. Cuidados de enfermagem. Tuberculose. Representação social.

#### RESUMEN

**Objetivo:** Comprender las representaciones sociales de personas con tuberculosis sobre la enfermedad y sus implicaciones para el sequimiento del tratamiento.

**Método:** Estudio descriptivo, con abordaje cualitativo, basado en la Teoría de las Representaciones Sociales. Se llevó a cabo en una unidad de salud municipal de la ciudad de Belém. Los participantes fueron personas con diagnóstico de tuberculosis y en tratamiento bajo observación directa, cuyo cuantitativo fue definido por la técnica de saturación de datos. La recolección de datos se realizó a través de una entrevista semiestructurada. Para analizar dos datos, utilice un análisis de contenido temático.

**Resultados:** Los registros convergieron en tres categorías: Representaciones de la tuberculosis y sus impactos en el diagnóstico; Como enfrenta el tratamiento: desafíos que enfrenta el seguimiento y la esperanza; y Construcciones de convivencia con la enfermedad en familia y sociedad.

**Consideraciones finales:** O vivir con una enfermedad transforma la vida cotidiana y las relaciones. La discriminación y el prejuicio denotan la necesidad de reconfigurar estas representaciones, para que el docente sea aceptado.

**Descriptores:** Enfermería. Atención de enfermería. Tuberculose. Representación social.

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### ■ INTRODUCTION

Tuberculosis (TB) remains recognized worldwide as an important problem that involves public health policies, requiring the construction of actions that involve its control<sup>(1)</sup>. During treatment, several factors directly interfere with its adherence, including: males give up more often; the economically disadvantaged population, illiterate and with education level below high school; alcohol consumption, smoking and other chronic diseases; people with previous treatment experiences, lack of reliability and dialogue with professionals and stigma of the disease<sup>(2)</sup>.

It is a fact that for every case of tuberculosis, Directly Observed Treatment (DOT) must be performed, as it is not possible to predict which cases will adhere. This strategy is more than just watching the deglutition of medications. It is essential to build a bond between the patient and the healthcare professional. To achieve this, it is necessary to remove the barriers that hinder better adherence, using social rehabilitation strategies, improving self-esteem, professional qualification and social demands<sup>(1)</sup>.

On the other hand, even with the advancement of years and technologies involving health and the reality of treatment through polychemotherapy provided by the Unified Health System (*Sistema* Único *de Saúde* – SUS), tuberculosis remains, around the world, an important problem involving health and thousands of people who become ill and die as a result of it and its complications<sup>(2)</sup>.

In this scenario, studies indicate that policies involving the health of these people regarding the prevention and control of the disease have shown, over the years, low effectiveness, little adherence to treatment, low progress in care, and despite this pathology having etiology, diagnosis and treatment, the high incidence of new cases, as well as mortality prevails<sup>(3)</sup>.

The historical series of the number of new tuberculosis cases in Brazil, per year diagnosed, the most recent date in 2017, were reported: North Region with 7,653, Northeast Region with 17,869, Southeast Region with 32,799, South Region with 8,074 and Region Central-West with 3,174 new cases of TB<sup>(4)</sup>. The number of deaths from tuberculosis in Brazil, Regions and States of residence per year of death reinforces this disease as serious and worrying. In 2017, the North Region had 481 deaths, the Northeast Region had 1471, the Southeast Region had 1920, the South Region had 451 deaths and the Central-West Region had 211 deaths<sup>(5)</sup>.

With high rates of new cases and mortality, besides the issues surrounding treatment, social psychology allows for the promotion of a dynamic approach that involves

representations built throughout the journey of a person with the disease, as it provides great importance to subjective evaluation of the patient's actions in the face of the disease over time<sup>(5)</sup>.

Since its emergence in history, TB brought a deep social impact that has existed over centuries, fueled by the lack of logical explanations for its emergence and permanence. This is not just a set of symptoms, an individual occurrence that affects people, but also a strangeness that threatens society and causes repulsion. It is, therefore, not just a biological entity, but a social phenomenon that leaves deep marks on individuals and social groups<sup>(6)</sup>.

In view of the Theory of Social Representations (TSR) and its applicability to this study on the implications for treatment follow-up, it also reveals the fight against this disease that has also transformed its psychological aspects. The theory enables to unveil phenomena within the consensus knowledge of the social universe and relationships, as well as the actions taken in response to them. Finding clues in the discourses of those who experience the problem also means setting out to build paths for effectiveness in disease control<sup>(6)</sup>.

In this sense, the understanding by healthcare professionals of the social representations constructed by patients in relation to the implications for tuberculosis treatment, allows them to understand the knowledge that underlies these representations about the disease and the practices on it, in addition to providing access to the bases for better decisions and practices, with actions aimed at more consistent care, thus contributing to improving the epidemiological profile of tuberculosis.

Therefore, the objective of the study was to understand the social representations of people with tuberculosis about the disease and its implications for treatment follow-up.

### **■ METHOD**

This is a descriptive study, with a qualitative approach using the Theory of Social Representations as a theoretical framework. The Consolidated Criteria for Reporting Qualitative Research (COREQ) instrument was used to support researchers to report information from qualitative research with transparency and quality.

The research included 20 participants enrolled in the tuberculosis program at the unit that was part of the research site. The inclusion criteria were: individuals aged 18 years or older; with a positive tuberculosis diagnosis and undergoing directly observed treatment at the study unit for a period equal to or greater than one month. The exclusion criteria were: people undergoing treatment for latent Mycobacterium

Tuberculosis infection and people with psychiatric disorders, whose diagnoses were obtained from the medical record.

The setting for developing the study was the Municipal Health Unit of Guamá (*Unidade Municipal de Saúde* – UMS), DAGUA District, in the municipality of Belém, considering that the UMS is the gateway for patients who will begin directly observed treatment, with the nurse being in charge of monitoring and controlling cases.

Data collection was conducted in May 2021, in a private space in the aforementioned health unit, with the collection lasting an average of 1 hour for each participant, conducted through a semi-structured interview with eight open questions.

Participants were approached by convenience and were conditioned on their attendance at the unit according with a schedule for directly observed treatment, as well as the data saturation technique being used as a way of delimiting the sampling of this study, which concerns on the quality of the interviews and the product collected, in addition to the repetition of the statements.

For data analysis, thematic analysis was used. This method aims to identify, analyze and report patterns or themes, allowing the organization and detailed description of the data set, to enable the interpretation of different aspects of the research theme<sup>(7)</sup>.

In this analysis, the collected data were transcribed in detail from their respective audio versions, subsequently reading and re-reading the interviews to familiarize themselves with these data. After, the generation of initial codes was established by coding the interesting characteristics of all the data in a systematic way, comparing the relevant data with each code and identifying common statements and meanings between the information. On that occasion, the elements collected were grouped into possible themes, bringing together statements with similar and relevant meanings and characteristics for each theme, which was reviewed to create a thematic analysis map, identified, and grouped using different colors for each theme. Furthermore, the themes were then defined to set the specificities of each area and, finally, the writing of the report with the integration of the data obtained with the questions that involve the object of study of the present research.

After this analysis process, the thematic units were identified and, later the text was subjected to new analysis, to understand in a more meaningful way the network of meanings resulting from the questions raised. Subsequently, the answers and common products identified were interpreted, with this being possible to construct three categories,

namely: Representations of tuberculosis and its impacts on the diagnosis; The faces of treatment: challenges facing follow-up; and Constructions of living with the disease in family and society.

Research approved by the Ethics Committee of the *Hospital Universitário João de Barros* under Opinion number 4.671.449, CAAE: 37747620.1.0000.0017. The study participants signed the Informed Consent Form (ICF) and remained anonymous throughout the study using alphanumeric codes, using the letter I (interview) followed by the sequential number of the interview.

## **RESULTS**

# Representations of tuberculosis and their impacts on the diagnosis

More than half of the participants understand tuberculosis from a physiopathogenic perspective, understanding it as a disease that affects the body. Alongside this knowledge, terms such as death, severity and treatment were present, as observed:

That TB is a bacillus that attacks the lungs, that the treatment is a bit long, but necessary to do it to be safe to finish and you need to have a lot of support from your family, because if you don't have correct guidance there might be evasion and you have to be careful not to have it again. (12)

It's a disease, that I didn't know about, I discovered it in 2018 when I was diagnosed. It's a bacterium that lodged in my lung and was corroding my lung tissue. (I4)

The answers converge towards an approach that aims to offer elements that provide information about the disease. The process that generates representations in the statement of subject I4 is highlighted when they, in an anchoring process, represents what tuberculosis is using the term "corroding" to indicate the illness caused by TB, in an attempt to classify, find a place and give a name for that was unfamiliar.

The dispute between social and scientific knowledge proved to be arduous. While science builds knowledge about the disease to provide more clarity about the reified processes of illness, on the other hand, the affections and practices produced in everyday conversations contribute to keeping images of old models that have not yet been surpassed in social thought, as observed below:

It's a curable disease that in the past there was no cure, everyone died, but not now, with legal treatment and everything you can be cured, now you have to follow the protocols correctly, so that it doesn't come back because if it comes back you can open the little coffin and bury yourself because you're going to die. (17)

I don't understand much about the disease, but it's a disease that has to be treated, right, take the medication correctly and not transmit it to other people, you have to wear masks, separate utensils, plates, glasses from other people to avoid getting it, take medicine, and get better soon. (18)

It is understood, then, that the construction of SR can occur through the relationship between these two universes of knowledge, with these representations corresponding to each intellectual and social reality experienced by these individuals.

Regarding the impacts of the diagnosis, half of the participants referred to issues linked to tuberculosis symptoms, the tests made and consultations. Another half of the participants related the moment of diagnosis as a surprise, fear and changes in their life routine. It is known that everything that is unknown causes fear and strangeness, additionally to being faced with a disease that has been stigmatized over the years. Observe the statements below:

It was very complicated (...). At the beginning it was very hard because I had to stop working and stay at home locked. (13)

I was very shaken by the news, I didn't imagine it had been [...] it was a surprise [...], but I wasn't too surprised either because I traveled a lot... I traveled a lot, I was in a lot of places, a lot of hotel rooms, I lived with a lot of people I didn't know. (117)

Tuberculosis was then represented as a reality that brings a sense of threat to life and routine, affecting the individual and incapacitating them, being capable of producing effects not only on the diseased body, but also on their relationship with the world and themselves.

Linked to this feeling of uncertainty, the desire to change, the sensitivity in identifying important points that should be reconsidered and reformulated permeate the network of meanings for some participants and reveal the second face of what tuberculosis means for these participants in a process that causes transformations. Observe the following:

A turning point, a problem that came to have a more delicate view of the family, to be careful, to give more importance to our routine, coexistence with the family, because I lived a lot on the street, at university, traveling with the company and not I was able to stay at home, and during this period I was able to spend more time with my family, I got closer to some people and moved away from others.(12)

This aspect reveals a counterpoint regarding the meanings linked to TB, if on one hand, the disease is represented by prejudice and suffering, on the other it allows the construction of a dimension that adds reflections on life in the face of this illness.

Finally, by making TB familiar, a process of adaptation, overcoming and recognition that treatment is a key figure of the healing process emerges in the statements.

It represents a phase that I have to go through, like everyone has their ups and downs and this was the first serious illness in my life, and it has been very challenging. I'm overcoming it. (I4)

A disease that they want to cure through treatment. (113)

It is worth noting that, given the construction of social representations by the interviewees diagnosed with tuberculosis, more than half of them manage to strengthen themselves in the face of the challenge of becoming ill and experiencing it, redefining, and reconstructing their life history and attitudes.

Thus, the representation constructed by each person or group reveals the faces of their own reality, of which three were observed in this study: the disease that continues to be seen as something bad and that denotes severity; awareness regarding changes in lifestyle and understanding of the world around and finally; tuberculosis meaning overcoming it through treatment conducted correctly.

# The faces of treatment: challenges facing follow-up

The representativeness of living with tuberculosis denotes the individual from a perspective of familiarity with the disease, considering that treatment has become not only a reality but decisive. Regarding the changes experienced by the participants when starting treatment, 22.22% of them portray the outpatient routine and medication; 27.77% referred

to the signs and symptoms of the disease; improvement in health status was present in the responses of 22.22% of participants; and discipline after starting directly observed treatment in 11.11% of the total; the other participants did not know or did not respond.

The characteristic signs of the disease present themselves as marks that emphasize these complaints and mean that the treatment is seen among other ways, with the diseased body. Observe below:

I lost a lot of weight, I don't eat properly anymore and to this day I still can't, I lost 21kgs and I have 11 to gain, but I'm not getting there. And also, the physical issue, I played sports, and it ended up like that.(I4)

If, on the one hand, these unpleasant sensations can put these users off, feeling better about the symptoms can also encourage them to adapt and follow the treatment correctly. Observe the following statements:

[...] It's very stressful, antibiotics every day, 4 antibiotics. But it's getting better, thank God with this medicine. (18) I started to feel better [...] I feltbetter, I gainedweight, myappetitereturned, I started eating well, and now I'm doing really well, thank God. (117)

From a positive perspective of the treatment and the understanding that good eating and living habits can help in following this to achieve the cure, the user signifies their actions and attitudes towards the disease to corroborate and do the drug treatment. As seen below:

Discipline, for sure, total nutrition, valuing food because I ate a lot on the street, I started eating healthy to give extra help in the treatment. I had good quidance. (12)

For other participants, the changes after starting treatment are linked to the outpatient routine, anti-tuberculosis medications seen as difficult to swallow and side effects. See the following statement:

But it's quite exhausting, in my case I wake up early in the morning, I have to take 4 pills on an empty stomach and it's very complicated, for me this is one of the worst parts, because the pill is large. (13)

When experiencing the process of tuberculosis illness, these difficulties become major challenges regarding

treatment adherence or make this journey a difficult task. In this sense, identifying the importance of reified knowledge on the role of the healthcare professional, especially the nurse, contributes to preventing treatment abandonment or failures. Observe:

I thought that when the test was negative I would be fine, until I stopped taking the medication. But when I returned to the unit, I talked to the nurse and he explained to me that it wasn't that, that I had to complete the entire treatment period. (119)

If it weren't for the guidance I received from the nurse, faced with so many difficulties, I probably would have given up on this. (120)

Treatment, then, requires patience, dedication and strengthening. In this way, the user identifies solutions regarding the importance of research, strategies and changes that should occur so that this treatment becomes more viable and less problematic. Observe the following statements:

[...] I believe there should be more studies on this, the reactions it gives, the size of the pill. (15)

I think there could be more research on medication like this, because before I never imagined that it would be difficult to undergo treatment, I thought that way because there are so many people who abandon it, you know, and now I can understand that it's not easy. (16)

Regarding on what the treatment represents for these people, all of them involved the meaning of the term hope, with hope also linked to the guidance of healthcare professionals and the responsibility towards the directly observed treatment.

The possibility of you being able to get rid of a serious disease, but because of the treatment you have the possibility of a cure. (I6)

It represents... well, pretty much everything, because when we're sick, we're nothing. (118)

Thus, social representations about treatment show that users construct meanings and significance about their actions on treatment, bringing into their networks of meanings, representations of suffering, difficulties, but that, on the other hand, they also understand the importance of this stage, incorporate changes to lifestyle, manage treatment in a positive way and with hope of cure.

# Constructions of living with the disease in family and society

When it comes to the family nucleus, it was evident that they welcome and experience TB together with the individual, with attention and care to encourage them and demonstrate the necessary support, as observed in the following statements:

They were my basis for supporting myself, especially when I had a drug reaction, because I was unable to do everything. So, they were my basis for following the treatment. (12)

I had to give up many things to undergo treatment, stay at home, it's an issue that affects your psychology a lot, so I think family is crucial, my relationship with my family is great. (13)

On the other hand, it is observed that even with the support network given by the family nucleus, there is segregation of some people who live with the diseased person and the tuberculosis patient himself, as shown in the statement:

With my family, I have support from my sister, I live with her, when I got home my brother-in-law immediately took a glass and said he didn't want me no harm but he also didn't want anyone to get this disease because it is transmitted in the air, he said, so we're going to mark your glass, but no one is going to stay away from you, we're going to keep talking to you normally, wear a mask inside the house, then it's going to be a disease that will require treatment because he said that his aunt underwent treatment and got better, but she only wore mask inside the house and the utensils were all separate. I had the support of my family, everything was great, especially in helping me quit alcohol. (18)

In this way, it is observed that the separation and division in the use of household utensils between people who have this emotional bond is evidenced by excessive care, which is often perpetuated even if this individual is no longer in the period of transmissibility risk.

When looking at how the relationship between research users and people in their social environment happens, it was identified that most of them reported rejection and prejudice in interpersonal interactions, followed by those who chose not to tell neighbors or friends about their diagnosis and finally, they observe that the relationship is normal.

In this sense, it was observed that prejudice surrounded by representations that permeate history remains part of the daily lives of these users and in this sense, suffering reaches the influence of stigma, of social processes resulting from discrimination, involving categorization, stereotypes, and social rejection. Observe the following examples:

Bad, very bad. Because they don't want to be close to what they think will pass to them. Then I was further away, more at home. (I1)

I've already suffered rejection from some people, but I ended up understanding them, maybe if I were in their place, I would do the same thing if I knew like I know today. I think that sometimes by not knowing, we don't have the necessary information, we end up being ignorant. (13)

Other users, to avoid discrimination, choose not to expose their TB illness in the social environment to which they belong, observe the statements:

Ididn't comment on it because although it has treatment, it's still a disease that people are like, you know, worried and there's a lot of prejudice surrounding the diagnosis, so I didn't comment. (16)

I had distanced myself from everyone around me, I lived inside home, so few people know what I'm going through. However, when I go to look for clients to clean their house, when I say I have TB they tell me to come back only after the treatment is finished. (112)

It is true that these findings reflect the understanding of people with tuberculosis that society upon learning of the diagnosis, would result in discriminatory behavior and for this reason they avoid exposing themselves, as a way of "shielding".

The results presented here revealed that the family environment, from the perspective of clients' relationships and interactions with the people around them, play a fundamental role, from suspicion to continued treatment. It is through this nucleus that strength and enthusiasm are reestablished in the face of the daily struggle that, besides issues involving illness, faces prejudice and discrimination in both social and work relationships.

Finally, it is up to healthcare professionals, through health education actions in the community, to demonstrate greater acceptance of people with tuberculosis, building strategies to reduce and eradicate discrimination, prejudice, and exclusion of ill people, providing information, clarifying

doubts, and adding the role of society in support networks for these individuals.

At the time of diagnosis, it is common to arise uncertainties regarding the disease and what it will be like to live with it in society, because it is something that is new in that individual's life. This aspect is identified in the light of the theory of social representations as the unfamiliar, meaning that, in the process of constructing their social representations, these people attach an image of a deadly and fearful illness. Thus, when faced with something that was previously unknown, they refer this condition to pre-existing knowledge, observing tuberculosis as a representation of something frightening and unexpected<sup>(8)</sup>.

Subjects add representations that are based on stigmas, beliefs and challenges that surround them and result in either negative or positive aspects upon the disease, which allows them to develop new perspectives and meanings that will be harmful or beneficial to them, as well as useful and necessary for daily life and coping with tuberculosis<sup>(9)</sup>.

Suffering from tuberculosis also triggers for these users the characteristic signs and symptoms of the disease and which are frequent in a body that is showing that something is not right, that is organically out of step with normality and that in this sense, not least reveals the feelings, sensations and emotions upon the new reality: having and living with the disease<sup>(10)</sup>.

In this context, treatment is essential in this journey of living and surviving. However, along this journey, users face difficulties in following the treatment. The main factors associated with issues involving correct treatment adherence are, among others, the user's lack of guidance about the disease and the treatment; social, economic, demographic and cultural barriers; difficulties inherent to the medication and the directly observed treatment in its routine at the healthcare unit<sup>(11)</sup>.

Therefore, it is understood that the treatment must be carried out completely, respecting the proper time for it. Thus, it is essential that healthcare professionals recognize the adversities and perceptions of users experiencing and dealing with this universe throughout their path, as this allows to develop actions and strategies focused on overcoming difficulties and reducing the treatment abandonment rate<sup>(12)</sup>.

From this perspective, well-conducted guidance helps to reduce abandonment rates. In this sense, it is important to prioritize the identification of barriers and challenges experienced by these individuals, providing a link of trust between professionals and users, making it necessary for professionals to be more aware of the aspects that interfere with treatment adherence and who also have skills to provide

critical-reflective care to these people about the importance of continuing treatment<sup>(13)</sup>.

Converging on this, it can be said that the correct adherence of a person with tuberculosis to treatment depends, among other factors, on their knowledge about the pathology, duration of prescribed treatment, regularity in the use of medications and sensitivity on the consequences caused by treatment interruption<sup>(14)</sup>.

Furthermore, tuberculosis was also mentioned regarding the perception of overcoming the disease due to the treatment and extra motivations such as familial and spiritual. As far as the family is concerned, it is seen as a safe haven, in which it is also understood as the essential support link for the individual to continue treatment correctly and have psychological support, this is because, according to the research of these authors, the countless situations experienced with the disease makes the person to present thoughts that undermine their will to live, so psychological influence is fundamental<sup>(15)</sup>.

In this sense, the family is represented as a reference for care and, in this way, can positively and significantly influence the individual's choices regarding their relationship with the health/disease process. Psychological influence interferes and can modify the behavior of people with tuberculosis and thus, family care is understood as relevant in this magnitude when it is well represented<sup>(16)</sup>.

In the social environment, it is evident that people who live with tuberculosis experience suffering not only due to the impacts of diagnosis, changes in routine and treatment, but that especially the constant presence of stigma and prejudice result in a negative perspective, exclusion and identification of a lonely person, where one perceives isolation from their social life<sup>(17)</sup>.

The issue of people with tuberculosis shows how much society still needs to mature concepts about the pathology and its contagion, including values that can add to health and treatment without the existence of prejudgments. As a result, they would not need to hide the disease to remain or to be included in the community and work. It can be observed, then, that social phenomena are represented through concepts that acquire meaning based on the perception and interpretation of individuals who conduct our relationships with people, guiding and organizing behavior and communications<sup>(17)</sup>.

Given the factors presented, the importance of the professional is evident, especially the nurse who is represented as an active subject of this care. Thus, among the strategies that must be achieved, the importance of maintaining a good relationship with the patient and family stands out,

being sensitive to their representations, creating bonds of trust, guidance on the health-disease process and all the consequences of discontinuing medications, even if they cause unwanted reactions, as well as facilitating access to healthcare services for tuberculosis patients<sup>(15)</sup>.

Finally, the limitation of this research was methodological, since the study was conducted during the period when services were reorganized as a result of the Coronavirus pandemic, therefore, the directly observed treatment routine also had its activities changed. In this sense, these factors contributed to the difficulty in recruiting participants. Furthermore, it is worth noting that significant stratified sampling was not possible according to the construction of the representations specified for each month of treatment as an adequate number of individuals were not identified for each class of this variable.

### FINAL CONSIDERATIONS

This research aimed to understand the social representations of people with tuberculosis and the implications for following treatment. Knowledge of this group's social representations about tuberculosis favored the understanding of the disease and how patients deal with it in their daily lives, despite the psychosocial context in which they are inserted.

Based on the results and conclusions, it is emphasized that nursing, as an active team in this care process, must remain present and sensitive to understand the various aspects: contexts and representations that surround the life of a person with tuberculosis. Considering this essential knowledge so that care goes beyond the limitations that are part of each individual's illness and thus provide these users with comprehensive, humane, and welcoming healthcare.

As part of this support, it is essential to work on issues that involve the suffering experienced, the difficulties in following treatment, prejudice, stigma, and discrimination that are part of social thinking. Therefore, a clearer approach by healthcare professionals is necessary for both the diseased person, their family and society in general, informing about the means of transmission of the disease, its transmissibility period and highlighting the need to minimize/eradicate the difficulties and culture of prejudice represented by the removal and exclusion of people with tuberculosis.

The healthcare model of the health-disease process, in addition to segmenting it, lead us to imagine that every disease has a cure, as evidenced in the study in question when reporting on tuberculosis, however it is clear that the Cartesian model does not take into account common

knowledge of the individual and their group, thus being the basis for the patient to continue the directly observed treatment and achieve a cure for tuberculosis.

Therefore, for health and nursing, it is necessary to understand the social representations of individuals affected by tuberculosis and undergoing directly observed treatment, since based on this empirical knowledge it is possible to proceed implementing care formats conceived from this configuration of naive knowledge. In this way, it is possible to proceed with the issue from the perspective of those who have acknowledged the disease and are recovering.

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