

## The discourse of individuals on feelings associated with coping with tuberculosis\*

### A discursividade do sujeito sobre sentimentos associados ao enfrentamento da tuberculose

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#### ABSTRACT

The objective of this study was to understand how a subject's feelings influence coping with tuberculosis. A qualitative study was developed with nine individuals undergoing tuberculosis treatment, living in a port city in Brazil. Semi-structured interviews were used in the empirical material production, and the French discourse analysis was used as theoretical-analytical framework. Results showed that cultural and social aspects influenced coping with the disease and determined the search for care and the therapeutic compliance. Self-medication, stigma, the feeling of fear in face of the critical nature of the disease, and the deficiency of professionals for suspicion and diagnosis contributed for users to search for health services late. The prolonged treatment, incidence of adverse reactions and early perception of cure hampered compliance with the treatment. Recognizing that the search for care varies according to the subjects' singularities directs the formulation of effective strategies and changes in tuberculosis control actions.

**Descriptors:** Tuberculosis; Primary Health Care; Emotions; Delayed Diagnosis; Medication Adherence.

#### RESUMO

Objetivou-se compreender como os sentimentos do sujeito influenciam o enfrentamento da tuberculose. Estudo qualitativo realizado com nove indivíduos em tratamento de tuberculose, residentes em município portuário do Brasil. Na produção do material empírico, utilizou-se a técnica de entrevista semiestruturada e, como referencial teórico-analítico, a análise de discurso de matriz francesa. Os resultados mostraram que aspectos culturais e sociais influenciaram o enfrentamento da doença e determinaram a busca por cuidados e a adesão terapêutica. A automedicação, o estigma, o sentimento de medo frente à gravidade da doença, a deficiência dos profissionais para suspeição e diagnóstico contribuíram para a busca tardia do serviço de saúde. O tratamento prolongado, a ocorrência de reações adversas e a percepção precoce de cura fragilizaram a adesão ao tratamento. Reconhecer que a busca por cuidados varia segundo as singularidades dos sujeitos, confere direcionalidade à formulação de estratégias eficazes e de mudanças nas ações de controle da tuberculose.

**Descritores:** Tuberculose; Atenção Primária à Saúde; Emoções; Diagnóstico Tardio; Adesão à Medicação.

## INTRODUCTION

Tuberculosis (TB), despite advances and incentives such as the DOTS (Directly Observed Treatment Short-Course) strategy and effective and affordable drug therapy, represents an increased burden of suffering and a major obstacle to socioeconomic development in the world<sup>(1)</sup>. In 2012, the World Health Organization (WHO) estimated that there were 8.6 million new cases of the disease and 1.4 million deaths. Brazil ranks 19<sup>th</sup> among 22 countries with the highest burden of TB reported in the world and accounts for 35% of the cases reported in the Americas. In 2012, 70,047 new cases of the disease were reported in Brazil, corresponding to an incidence rate of 36.1/100,000 inhabitants. Every year, approximately 4,500 people die from TB, making it the fourth leading cause of death from infectious diseases and the leading cause of death in patients with AIDS (Acquired Immune Deficiency Syndrome)<sup>(2)</sup>.

Therefore, to understand the factors that influence the persistence of TB in the ranking of communicable diseases requires a comprehensive assessment of the situation and consequent implementation of effective disease control measures.

Delayed TB diagnosis and noncompliance with treatment constitute barriers to controlling the disease, because they give rise to a poor prognosis and further spread of the disease. Delayed diagnosis has been defined as the interval between the onset of symptoms and the start of treatment, and may be related to characteristics of the subject (socio-economic context of the individual and family, ethnic/racial and cultural factors, perceptions of the health-disease process, behavioral and religious issues, severity of the signs and symptoms) and health services (difficulty of access, users not feeling well-received, low priority in the search for respiratory symptoms and intra-household contacts, and low level of diagnostic suspicion)<sup>(3-4)</sup>.

In terms of the cultural, psychological, and behavioral aspects, it should be emphasized that people suffering from TB are dissociated from their feelings who build

meanings of health that are disclosed in inter-discourse, relationships, and inter-subjectivity. These feelings, through interpretation, generate meanings that translate how they face the disease and seek out medical assistance, and influence the way treatment is viewed<sup>(5)</sup>.

An understanding of the factors that influence delayed diagnosis and compliance with treatment, from the perspective of those suffering from TB, goes beyond concepts and techniques and reinforces the need to recognize that each person has a unique way of understanding and coping with the disease. Punishment or chastisement; inability or dependency; lack of health; imbalance; functional impotence, indisposition, or apathy; unhealthy practices; changes in the pace of life; precarious financial conditions; not being at peace with oneself, others, and the world; and the presence of external and/or internal aggressors are possible popular expressions that provide a range of meanings and help us in our perception of the ill individual<sup>(6)</sup>.

The different concepts attributed to health are intrinsic to individual values and scientific, religious, philosophical, and cultural concepts<sup>(7)</sup>. In every experience, people create and recreate meanings and symbols of their health-disease process and the forms of prevention, treatment, and healing. To understand the factors that cause changes in behavior and practices, it is necessary to discuss the meaning of behaviors, which express perceptions, values, symbolic representations, power relationships, beliefs, and feelings. It is recommended, therefore, to take into account the subjectivity inherent to the subjects and their representations of the health-disease process<sup>(8)</sup>.

Based on this perspective, it is essential, in providing TB care, to exchange the current traditional model, which centers on the disease, for a dialogic model that recognizes the subject and his or her concepts and knowledge, which cannot be depreciated by health professionals. Therefore, measures need to be adopted that transcend the biological body and focus on the

transformation of the values, ideologies, and concepts of society<sup>(9)</sup>.

Thus, taking into consideration the interpretation associated with contracting TB, delayed diagnosis, and the search for supplementary care alternatives as factors that influence compliance with official treatment, we believe it is important to understand how the feelings of the subject influence the way in which the disease is faced, which is the objective of this study. We do not intend to overemphasize these issues in the analysis, but rather to scrutinize the discourse of the subjects with TB in a desire to contribute to the building of knowledge that will mitigate the illness of others and circumvent other approaches that do not result in healing, through changes in health practices focusing on users with TB.

## METHOD

This is a descriptive, qualitative study that was conducted in Cabedelo, a port city in the metropolitan region of João Pessoa (state of Paraíba), which stands out epidemiologically for its high incidence of TB cases.

To establish the group of study participants, a brief epidemiological profile of the disease in that city was prepared. In 2012, there were 31 new cases of the disease in the city, with an incidence rate of 46.59/100,000 inhabitants, higher than the national rate<sup>(10)</sup>. During the period of the study, 18 cases of tuberculosis (in treatment) were identified by the Information System for Notifiable Diseases. From these cases, we established the group of study participants. We excluded cases of patients who were abandoning treatment, as well as those under age 18, those living in areas with an extreme risk of violence, and those who were institutionalized (either in a hospital or as inmates in prisons). Based on these criteria, nine subjects were selected to participate.

As the tool for production of the empirical material, it was decided to use the semi-structured interview technique, based on a script that included the social characterization of the interviewees (gender, age, education, religion, occupation, lifestyle, i.e., smoking

and alcoholism) and issues related to delayed diagnosis and compliance with treatment, by examining the attributes of individuals with TB (concepts of the health-disease process and of contracting TB, self-medication, experience of stigmatization, and attitudes of abandonment, among others) and characteristics related to health services (access barriers, resolution of the problem in official health units, trajectory of the user until diagnosis of the disease).

The interviews, which took place from August to October 2011, were scheduled in advance and held in people's homes, in places that ensured privacy for individuals to respond to our research questions. The interviews were recorded with the consent of the interviewees and transcribed afterwards.

The theoretical and analytical framework used in the empirical data analysis process was the Discourse Analysis (DA), originated in France, which deals with the historical determination of meaning processes, taking as its central focus the relationship between language and its production context. Furthermore, this theory shows that there is no discourse without a subject and no subject without ideology, with language serving as a social space for debate and conflict<sup>(11)</sup>.

To perform the analysis from the perspective of DA, there were three stages: the first was characterized by the formation of the *corpus*, defining its limits, establishing focuses, and starting the analysis work by recapturing concepts in a constant back and forth between theory, consulting the corpus, and analysis, transforming the linguistic surface into the discursive object. The second stage consisted of moving from the discursive object to the discursive process, based on observation of the text meanings, identifying the discursive sequences and fragments. These meanings are determined ideologically, not expressed in the essence of the words, but in the discourse of the subjects<sup>(5)</sup>. The third step entailed grouping the discursive fragments, from which three discursive formations (DF) emerged: "The relationship between the feelings of the subjects in having contracted

TB and the coping strategies used”; “Seeking out official health services due to worsening of the symptoms”; “The feelings of the subjects toward treatment and the search for supplementary care.”

The research project was submitted to the Research Ethics Committee of the Center for Health Sciences, of the Federal University of Paraíba (UFPB), in accordance with the guidelines of the research protocol contained in Resolution CNS 466/201. The study was approved on December 17 2008, under No. 0589. Each interviewee freely chose to participate in the study, signed a Free and Informed Consent Form, and was assured that the information would remain confidential. In order to ensure the anonymity of the research subjects, respondents were called E-1, E-2, up to E-9, according to the sequence in which the interviews were conducted.

## RESULTS AND DISCUSSION

Understanding the “way of living” of subjects with TB provides insight into how life conditions generate meanings and interpretations in the discovery of the disease and coping with it. Thus, the social context of the research participants was taken into consideration, supporting the view that the social evils of health shape the way the subject deals with the disease. The city where the interviewees live has a high population density of 1,815.57 inhabitants/km<sup>2</sup> with a 54.8% incidence of poverty, ranks second on the Municipal Human Development Index of the state of Paraíba, Brazil (at 0.757), has a 10.7% illiteracy rate (in Brazil, the rate is 9.6%), and only 51% of households have proper sanitation (as opposed to 61.8% in Brazil as a whole)<sup>(12)</sup>.

All of the participants reside on the outskirts of the city, and five of them live in hazardous substandard housing. The interviewees have access to clean water and electricity, but waste disposal is not adequate. All of them have health services available, with a health unit close to their homes and a general hospital in the city, as well as outpatient services. They may also be referred to the

reference hospital in João Pessoa (a neighboring city within the same metropolitan region).

The link between poverty and TB is tied to socioeconomic indicators such as abnormal agglomerations, poverty, unemployment, and overcrowded and unhealthy housing conditions, contributing to the spread of TB in the community and consequent increased incidence of the disease. In addition, reduced access to health services, likewise a reflection of poverty, can lead to late diagnosis and delays in starting treatment<sup>(1,13)</sup>.

Most of the interviewees have a low educational level (six years of schooling), which illustrates the low socioeconomic development of these subjects and constitutes a barrier to obtaining information about TB. A study in Ethiopia on TB diagnosis found that patients with more than eight years of education were less likely to put off getting a diagnosis<sup>(4)</sup>. Most of the interviewees work in the informal market or are unemployed. Only two subjects had formal jobs. A study conducted in China found that economic barriers, in terms of low income, were a factor that influenced the behavior of individuals in relation to seeking medical help and in delayed diagnosis of TB<sup>(13)</sup>.

As far as the lifestyle of the study participants, of the total of nine, five have been smoking for more than 10 years, six claimed to be alcoholics, and two said they use illegal drugs. It is important to note the connection between these behaviors and the difficulty in complying with the treatment.

The interviewees were asked about their concepts and feelings toward TB, resulting in Discursive Formation I, with its discursive fragments presented in Tables 1 and 2.

**Table 1:** Feelings experienced by users upon confirmation of the diagnosis of TB. Cabedelo, PB, Brazil, 2011.

Discursive Sequences	Discursive Fragments
...user is afraid of death	<i>... I thought I was going to die. I'm very afraid of dying, not death itself, but of having to leave my children. [long sobbing] ... (E-5)</i>
Fear of death; peace upon discovering that the disease is curable	<i>It made me cry, I cried a lot... I thought I might even die, lose an organ in my body, such as a lung or liver or something like that. I saw on television that TB can be cured, and then I was more at peace about getting better. (E-6)</i>
Contemplation of suicide	<i>A lot of things went through my head ... To do something stupid ... (E-7)</i>
Shame and social rejection, idea of scorn and loss of health	<i>... I was afraid. I was sad. This had never happened to me before, because I thought it was a horrible disease I'd gotten. I didn't think there was any cure for it... I felt ashamed to say I had tuberculosis. I don't tell anyone ... When you have a sickness like this, you feel rejected by the whole world. I was very distressed with my life. [sobbing] (E-4)</i>
Idea of scorn and no longer being healthy	<i>That I would be scorned by my family. I felt that I would no longer be healthy with this problem... (E-7)</i> <i>I feel scorned. I live alone and I don't even like to say the name of this disease. My father died of tuberculosis. I feel ashamed. My brother also had it... It's hard for me to seek help. I really don't like to. I don't like to go to the doctor or the hospital. I've been living here for one year and three months and if you go to the health unit you don't feel welcome, which makes me furious. At the health unit, because of my sickness, people started gossiping. (E-8)</i>
Absence of negative feelings upon learning that the disease has a cure	<i>I didn't feel much, because I'd always heard it has a cure. They said it was simply a matter of doing the treatment, that it was curable. (E-3)</i> <i>I was okay. Because they said it was curable. (E-1)</i>

**Table 2:** Self-medication as the initial care strategy in the early stage of the disease. Cabedelo, PB, Brazil, 2011

Discursive Sequences	Discursive Fragments
Self-medication: Use of allopathic medicine and home remedies	<i>I took Anador when I had fever... I would drink matruz [medicinal plant] tea with milk. I don't like going to the hospital. I get nervous. You don't always receive good service and there are a lot of people. (E-8)</i> <i>I've been coughing for almost ten years... I took cough medicine on my own. I'd go to the drug store and get a cough medicine. I'd take it and feel better. I went on for years like that... (E-4)</i> <i>I took medicine at home. When I had pain I'd ask someone more knowledgeable for information. I'd take tea... First I took medicine at home, because I had headaches, until I couldn't stand it any longer... I was one month at home sick... I thought it wasn't anything serious ... (E-9)</i>

**Discursive Formation I: The relationship between the feelings of the subjects in having contracted TB and the coping strategies used**

In the sequence of discourses contained in the fragments, it is possible to identify feelings related to death—the relationship established between the TB sufferer and death. There is both the expectation of physical death, as well as that of social death, arising from the idea of scorn and rejection. The feeling of fear is common in both situations. In the case of E-5, there is a condition that immediately produces it, in that she was suffering from extreme malnutrition and at the height of the disease getting worse.

In these discursive sequences (DS), there are feelings that are part of the discursive memory and that characterize the imaginary construct of the disease,

evident in the paraphrastic process in which the same sedimented and crystallized discourse is maintained that contracting TB means dying or being isolated from others—the latter due to lack of knowledge and the stigma. However, in more faded tones, but in a lower proportion, it can be noted that other discourses express knowledge about the disease being curable, which contributes toward mitigating the discourse focused on the idea of death and evocative of stigma and prejudice, such as: “I didn't feel much, because I'd always heard it has a cure. They said it was simply a matter of doing the treatment, that it was curable” (E-3).

In the collective imagination, fear and aversion toward the disease are explained by ignorance of its causes, the ineffectiveness of its treatment, and the patient's association of the disease with deviant behavior

in relation to social norms. “The horror in the face of tuberculosis ends up making it a taboo, an object of interdiction, and its extreme symptom is stigmatization of the patient and his or her consequent isolation”<sup>(14)</sup>. Going back to the discursive fragments from the first table, it can be seen that one possible strategy for coping with the disease is suicide, as denoted by the comment by E-7 “*to do something stupid.*”

In Norway, a study on the causes of delayed TB diagnosis pointed out that one of the reasons on the part of patients is the stigma arising from contracting TB<sup>(15)</sup>. In many countries, due to cultural characteristics, the difficulties faced by patients are aggravated by the social stigma toward the disease, which has an influence on their seeking medical help and complying with the treatment, and even encourages them to abandon it<sup>(15)</sup>.

As far as strategies used by those with TB when confronted with evidence of complications, the table below contains the DS in which the subjects reported self-medication as the first intervention. This is a cultural practice and generates meanings stemming from the millennial culture of self-care, primarily through the use of home remedies, which in modern times reinforces the biomedical concept centered around allopathic medication without the consent of a qualified professional. Behavioral, cultural, and social traits are identified that show the particular way in which subjects with TB in a given location interpret the discovery of the disease and the first approach toward dealing with it.

The irrational practice of self-medication heightens the risk of adverse events and masks diseases, which can lead to a delayed diagnosis<sup>(16)</sup>. With regard to self-medication by those suffering from TB, it usually masks the disease, followed by a worsening of symptoms, delayed diagnosis, and continuation of the transmission chain.

Self-medication produces meanings arising from the ideological formations of the subjects who engage in it. Self-medication reflects the growing medicalization and pharmaceuticalization of modern society, which is

expressed in biomedical ideology. At the same time, the standardization of its prescription promotes a gradual lay appropriation of the criteria for medical decisions, which is reproduced in lay solutions to common health problems<sup>(17)</sup>.

In a study on delayed diagnosis of TB conducted in Ethiopia, there was a significant connection between self-medication and delayed diagnosis, in which 61.7% of the interviewees initially sought informal health services, such as traditional healers (27.1%) and drug stores (31%)<sup>(4)</sup>. Another study, conducted in Ghana, found that in the early stages of the disease, most patients did not recognize their signs and symptoms as characteristics of TB, and used common cough medicine<sup>(18)</sup>.

In summary, strategies or options for coping with TB were noted that illustrate a lack of knowledge and an extension of the concept of the medicalization of health, in this case cloaked in cultural traits, updated by easy access to drugs, and consumed based on the saying “everyone’s got a little bit of doctor in them.” From the interdiscursive perspective, there is a blend of tradition and updated information used to take action to resolve health problems. Undoubtedly, in this case, self-medication has a bearing on delayed diagnosis, because this strategy is used before seeking out medical help.

### **Discursive Formation II: Seeking official health services due to worsening of the symptoms.**

In relation to what leads the subjects to go to health services, they report that they seek medical help when they notice that the symptoms are getting worse. As a result of the delay in seeking medical assistance, six of the interviewees had to be hospitalized. Among the perceived symptoms were hemoptysis, extreme tiredness, vomiting, constant fever, and chest pain, as seen from the discursive fragments in Table 3.



**Table 3:** Interpretation of the signs and symptoms of the disease that led the subjects to seek medical help. Cabedelo, PB, Brazil, 2011.

Discursive Sequences	Discursive Fragments
Tiredness, difficulty walking	<i>I felt it was serious. I started getting very tired. I couldn't even walk. Because it was night. I only went at dawn, because I was very tired. I waited two months before going to the hospital ... (E-7)</i>
Two month delay before seeking medical help	
Hemoptysis	<i>Because I saw blood. When I spit, there was blood in the saliva. Then my daughter told me to go to a doctor and took me to the Clementino. There they told me that I'd be hospitalized for three days, but I ended up staying 19 days ... I was very afraid to be hospitalized ... it was because of that. I was afraid to find out and then have to stay in the hospital ... (E-4)</i>
Immediate seeking of medical help	
Initial perception of common cold symptoms	<i>I spent one month sick at home... I didn't think it was anything serious ... (E-9) ... I only went to the hospital when I started to actually vomit. I thought it was a normal fever. When I started getting worse, I went to the doctor ... (E-3)</i>
Seeking of medical help due to worsening of the symptoms	

The feeling of fear linked to TB is not attributed to the disease, but of hospital confinement, which the disease has the potential to cause. Fear, from the evidential point of view, is truly one of the elements related to delayed TB diagnosis.

It was also noted that the symptoms of the disease are interpreted as not being serious but rather associated with respiratory diseases, especially a cold, which also contributes to the delay in seeking medical help. Once again, it was observed that the cultural trait is a determining factor in the configuration of the health-disease-care process. In this sense, the severity of the condition is the main element that leads the person to seek medical help. Until then, the subject, it can be said, takes on the role of doctor, and care is up the individual and his/her family. In the shadows of the discourse, it is also fear, revealed by the severity of the symptoms, that leads the sick person to go to health services and seek professional help.

The discourses indicate that, when seeking medical help, there are other aspects that contribute to the delayed diagnosis, such as professionals lacking training

in the diagnosis and suspicion of TB, and lack of resolution in Primary Health Care services, as seen in the DS:

*... I was coughing a lot, that dry kind of cough. I visited the PSFs [Family Health Program] a lot. I went to the doctor, who said it was an allergic cough. He prescribed a cough syrup, but it didn't get better. I went to several doctors, I went to the PSF here. In the emergency room I took an X-ray and they said I didn't have anything, but it kept getting worse... I went to an allergist and she said that due to my age it wasn't an allergy and told me to take a lung X-ray. That's when I took the X-ray in the clinic. I discovered what it was at a private [health service]. (E-2)*

*... I don't trust the PSF anymore, just for very simple things. If I see that it's something more serious, I go to a private clinic. (E-2)*

It can be observed that once subjects with TB are unable to solve the problem of the disease on their own, they relinquish control over their own care and seek medical help. However, the failure to resolve the subjects' problem in the public health service unit results in a delayed diagnosis. The following are also noted: a feeling

of mistrust that is generated, with a consequent break in the link between these health system users and the local health care unit; the social vulnerability of these users; and the expenses incurred with private health services.

Since 2003, the WHO has manifested its concern regarding the preparedness of health teams to assume responsibilities involving TB control activities, an issue that emerges in the wake of decentralization and integration of disease control in Primary Care Services, and that this is one of the challenges to the sustainable expansion of the DOTS strategy and for achieving the goals of detection and successful treatment<sup>(19)</sup>.

According to a survey conducted in Norway, it was identified that, among the factors that result in delayed

diagnosis of TB, the main one related to health services was the failure to properly diagnose the disease at its onset, despite the characteristic symptoms<sup>(15)</sup>.

### Discursive Formation III: The feelings of the subjects toward treatment and the search for supplementary care

In terms of the perspectives toward treatment, those with TB described the feelings they experienced at the time the therapy was explained to them, particularly the feeling of “surprise” concerning the length of time of the treatment and adverse reactions to the drugs (Table 4).

**Table 4:** Attitudes and feelings in relation to treatment of the disease. Cabedelo, PB, Brazil, 2011

Discursive Sequences	Discursive Fragments
Long duration of the treatment	<i>I thought “the treatment is going to be very long!” For me, six months is an eternity. I thought it would be three months, or two months, and then be over and I’d be better. (E-4) ... I was surprised at how long you had to take the medication. (E-7)</i>
Improvement due to the treatment and change of habits	<i>Thank God! I think it’s my efforts that are helping me get better. I don’t go out anywhere. I’m concerned about the schedule for taking my medication ... (E-2) ... The medication is helping me get better, along with all the rest I’ve had ... Now I know what to do not to get this anymore: cut back on smoking; don’t get wet in the rain; and don’t expose myself to a lot of dust. (E-3)</i>
Adverse reactions and frailties while undergoing the treatment	<i>In the beginning when I started taking the medication, I felt sick, agony, and my heart was very affected. Even now when I take it, I feel sick. When I take it, I vomit a little. (E-7)</i>
Adverse reactions and abandoning the treatment	<i>... I thought about leaving the hospital and to stop taking the medication due to the pain in my bones... I thought about stopping, but my daughter said that if I stopped it would be bad for me, and at the hospital they said that if I missed taking the medication for one day, it would come back again. They said that it comes back stronger. (E-4) ... I’ve thought about stopping, because I feel I’m getting even weaker and every day I take the medicine I’m getting thinner... I felt better; I started taking it and stopped afterwards... When the six months were over, I stopped. I was supposed to go back for a checkup, but I wasn’t interested. I didn’t call afterwards and when I came to live at my mother’s house it started all over again... I thought, “After six months I’m fine. Why should I go back again?” (E-5)</i>
Premature perception of healing and abandoning the treatment	<i>I stopped, I quit. I didn’t take anything for a month, two months before finishing. I didn’t feel anything. I wasn’t tired. Then I had a relapse and it was worse. I went to the Clementino. I was really down. I didn’t tell anyone. (E-7)</i>

In these discursive fragments, it can be noted that adverse drug reactions, the prolonged length of the therapy, and premature perception of healing weakened compliance with the treatment and fostered attitudes toward abandoning the therapy.

Different studies on the factors associated with abandonment of TB treatment have been conducted in Brazil, due to the importance of therapeutic compliance for the success of the treatment and disease control. Among the causes for abandoning treatment, the following aspects were identified: being male, smoking,



alcoholism, and illicit drug use; history of prior hospitalization<sup>(20-21)</sup>; insufficient information about the disease; drug intolerance; discontinuation of treatment due to regression of the symptoms; prolonged length of the treatment; and the large amount of tablets ingested<sup>(22-23)</sup>.

Regarding the search for supplementary care alternatives, the predominance of religious discourse and belief in God for healing can be noted in the following discursive fragments.

*I used to go sometimes to the Universal Church to see if I'd get better. But they'd say that only those who have faith get well... I think I'm getting better... I think it's actually the pills, and the food, because in the past I didn't eat and now I'm eating right. In my opinion, God has helped me a lot. (E-4)*

*I think I'm really getting better... and if it weren't for God I'd surely be dead. First Jesus, then the medicine. If it weren't for Jesus I'd already be in another world. (E-9)*

*With God's help and by going to church, I think I'm getting better, but not from the medicine. Because the more I take it, the thinner I get. People that know me say I'm getting worse than I was. I hear the Word of God, and I don't cough as much as I used to. My mother is also helping me. I'm taking the medication just for the sake of taking it. (E-5)*

A duality of healing concepts can be noted in the first two discourses, as revealed in terms of compliance with treatment and the spirituality of the subjects. In the third discourse, the worsening of E-5's disease led to disbelief in the therapeutic regimen and the hope of improvement was instead focused on divine intervention.

The concept of health based on religion is still rooted in the discursive memory of many individuals and continues to produce the same effects observed for millennia, when the magical-religious or ontological concept prevailed, according to which disease arises from

the action of supernatural forces, and healing is subject to divine will or sacred rituals<sup>(7)</sup>.

This duality of concept reveals feelings associated with the world of official medicine and the cultural world, especially religion, because even during treatment the subjects also take care of themselves, demonstrating how their cultural world is a crucial factor. Thus, the fact that health services do not take into account the feelings directly related to care contributes to delayed diagnosis and weakens compliance with the treatment.

Therefore, health services need to be organized from the standpoint of integrality, where the core belief underlying the concept of health services is that users should be cared for and respected according to their requests and needs<sup>(24)</sup>. Health and nursing care provision should value the subjectivity and individuality of each person, seeking to understand the concepts individuals have of the health-disease process. This constitutes the central pillar in the quest to minimize harm and social vulnerability, in order to achieve success in the therapeutic process and higher levels of quality of life for users of health services<sup>(25)</sup>.

## CONCLUSION

The cultural, behavioral, and social aspects of subjects with TB greatly influenced the delay in diagnosis and compliance with treatment. The cultural practice of self-medication, identified as the first coping strategy used by TB sufferers, contributed to the belated seeking of medical help and the consequent delay in diagnosis and worsening of the disease. Hence, the perception of the severity of the disease was the determining factor for seeking medical help. However, the feeling of fear experienced by subjects with TB concerning the possibility of hospitalization also promoted delayed diagnosis.

It is also worth noting that the stigma associated with the disease influenced the delay in seeking medical help and compliance with treatment. Another important aspect that resulted in late diagnosis was the lack of

confidence in health services due to the shortcomings of professionals concerning suspicion and diagnosis of the disease.

Regarding the behavior of TB sufferers toward official therapy, it was observed that adverse drug reactions, prolonged therapy, and premature perception of healing weakened compliance with treatment, inclining them to abandon it. As mentioned earlier, integral and inter-sector-based care of subjects with TB is very important. It takes into account the peculiarities of the socioeconomic and cultural context of individuals, as well as the feelings involved in living with the illness, which have a direct

impact on the seeking of medical services and compliance with treatment.

Therefore, relationships need to be built that connect individuals with TB to health professionals, based on a dialogical approach that enables discovering the particularities and feelings which determine how the disease is faced and, consequently, ensure long-term care and compliance with treatment.

It is also suggested that care practices for those suffering from TB be redirected to health education, taking into account the particularities of users and the unique features of different social realities.

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