



LIVE/COPE WITH TUBERCULOSIS/HIV AND THE MEANINGS REPRESENTED BY THE ILLNESS PROCESS: A DISCOURSE ANALYSIS¹

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ABSTRACT

Objective: analyze the meanings produced by the illness process and how they affect people living with tuberculosis (TB) and the human immunodeficiency virus (HIV). **Method:** this is qualitative research, with theoretical-methodological approach of French Discourse Analysis (DA), carried out in a referral center for chronic infections, within the period from January to July 2015. A semi-structured interview script was used to collect primary data. For the collection of secondary data, we used the record and follow-up book for TB treatment; the Notification Disease Information System (Sistema de Informação de Agravos de Notificação [SINAN]); and the TB patient control system. **Results:** 6 people undergoing TB and HIV treatment were interviewed and 3 discursive blocks emerged: "Tuberculosis and HIV: circulating meanings;" "The patient-practitioner bond and use of incentives in treatment continuity;" and "Conditions that influence the illness process." **Final remarks:** the theory that these health conditions affect only certain individuals remains circulating in society, favoring prejudice, late diagnosis, and difficulty in complying with treatment. Thus, public policies and health promotion actions taken by health managers and practitioners are needed to contribute to knowledge (de-)construction and comprehensive and longitudinal care both for those undergoing treatment and their family members.

Keywords: Coinfection. HIV. Tuberculosis. Public health. Chronic disease.

INTRODUCTION

Tuberculosis (TB), an infectious disease known as a global public health problem, ranks ninth as the cause of death in the world and mainly affects individuals living with the human immunodeficiency virus (HIV)⁽¹⁻²⁾. Its morbidity and mortality rates are higher in developing countries such as Brazil⁽³⁻⁴⁾.

Although, until the mid-1980s, TB was considered controlled in developed countries, with the advent of the HIV epidemic and the acquired immunodeficiency syndrome (AIDS), there was a resurgence in the number of cases, changing the epidemiological profile and TB control⁽⁵⁾. This scenario changed the epidemiological features of these conditions,

making control and treatment more complex due to the prognosis of affected individuals⁽³⁾. Furthermore, TB/HIV co-infection causes significant distress for these individuals and their family members, as their daily lives are drastically affected, leading them to leave their jobs and withdraw from social and family life⁽⁶⁻⁸⁾.

Illness due to TB/HIV co-infection is both a pathophysiological and a subjective process, permeated by discourses, knowledge, and customs conceived throughout human history, as well as supported by old and forgotten formulations – the interdiscourse about the disease and the person who lives with it, affecting the way in which an individual interprets and (re)signifies the experience⁽⁷⁾.

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In this sense, the individual who experiences such a reality may be regarded as the spokesperson for a set of social concepts, crossed by religious and cultural issues, among others, which affect the construction of their subjectivity and their process of reframing the theories of health and disease⁽⁹⁾.

Thus, various possibilities for the production of meanings and interpretations of falling ill may arise, which depend on how these people face, deal with, or respond to their social environment^(7,10).

In the health sector, a predominance of the biomedical model still exists, so it is necessary to reformulate 'words and things,' as well as a reading of the multiple senses and meanings of falling ill, in which the symptom (signifier) does not have as its sole referent the biological aspect (signified), but a web of culturally shared and ideologically shared meanings⁽¹¹⁾.

Thus, this study analyzes the meanings produced by the illness process and how they affect people living with TB/HIV.

METHOD

This is a descriptive, exploratory qualitative research, derived from an MA dissertation, approved under the Opinion of the Research Ethics Committee (REC) No. 860,668, which used the theoretical-methodological approach of French Discourse Analysis (DA). Epistemologically, DA is based on linguistics, materialism, and psychoanalysis; to do this, it sees language as mediation between human beings and the social and natural reality. Thus, AD makes it possible to see the health-disease process through time and space in human practices. Therefore, words only produce meanings when they come from the discursive formations in which they are inscribed, i.e. something that in a given ideological formation and socio-historical situation determines what can and should be said. So, the discourse is not paralyzed, it is a process in constant movement, it is not a collection of texts, but a practice⁽¹²⁾.

That said, the analysis proposes to know the meanings produced by the discourses beyond what has been said, looking for cues

and clues that enable the apprehension of what remains 'unsaid' in the language, by means of unconscious and ideological positions. Discursive analysis requires understanding that interpretive gestures are not unique in themselves, but provide new meanings, according to the position that the individual occupies when speaking⁽¹³⁾.

The study was carried out in a city located in the center-east region of the State of São Paulo, which had 254,484 inhabitants in 2020, within the period from January to July 2015, at the Chronic Infection Care Center (Centro de Atendimento de Infecções Crônicas [CAIC])⁽¹⁴⁾. This is a secondary care service, where the following conditions are treated and monitored: HIV/AIDS, viral hepatitis, syphilis, TB, leprosy, and other infectious and contagious diseases. Take place in this setting medical appointments with infectious disease specialists, nursing consultations, psychological care, social assistance, vaccination, rapid tests for HIV, viral hepatitis (B and C), and syphilis, exam request and scheduling, tuberculin test (PPD), screening and monitoring of communicants, referral to tertiary care services, supervision of cases along with primary health centers (unidades básicas de saúde [UBSs]) and family health centers (FHCs), health education, and support group for family members of people undergoing treatment. From January 2014 to June 2015, this municipality had 12 cases of patients co-infected with TB and HIV. Out of these, 3 people were admitted to an institution, 6 were undergoing outpatient treatment, and 3 deaths were not recorded as due to TB. Care for these individuals is provided on a monthly basis until a cure for TB is achieved, then follow-up care takes place every 2 or 4 months, depending on the general health conditions of each person, and visits to the CAIC consist of individual comprehensive assessment, appointments, exam requests, and delivery of drugs for HIV treatment.

Data collection was divided into 2 stages. First, the Ministry of Health's record and follow-up treatment book for TB cases, the TB patient control system (TBWEB), and the Notification Disease Information System (SINAN). At this stage, sociodemographic

data (age, sex, origin, education, marital status, income, and occupation) and the history of TB treatment of each person were sought, in order to characterize the profile of research participants and gather the production conditions belonging to each of them. It is noteworthy that there was prior authorization by the REC, as well as by the institution's coordinator, to access data and use an instrument built by the authors themselves to collect the information described above.

In the second stage, individual interviews were conducted with people undergoing TB/HIV treatment. The inclusion criteria to participate in the study consisted in: to be diagnosed with TB/HIV, undergo treatment for more than a month at the infectious disease's clinic, be not institutionalized, and be over 18 years of age. Individuals who did not meet the inclusion criteria or did not accept to participate in the study were excluded from it. Thus, 6 individuals participated in the study, who were informed regarding the research objectives, the preservation of their anonymity and the confidentiality of information, as well as their right to abandon the research or withdraw their consent at any time.

These people were met before or after medical appointments and/or nursing consultations. The interviews were conducted by only 1 researcher, at the CAIC, in a reserved place, to ensure the confidentiality of information provided by the study participants.

Six people living with TB/HIV and undergoing treatment at the specialized health service were interviewed. It is noteworthy that one respondent asked his mother to be monitored during the interview and so it was done. It was also noticed that people mentioned, in their discourses, some family members who, in a way, are present in their daily lives. The selection of individuals was done by convenience sampling. A semi-structured script with the following guiding questions was used:

- How have you been during this treatment period?
- Is this the first time you undergo tuberculosis treatment?
- How did you feel when you heard that you have tuberculosis?

- How do you feel about having to live with HIV and TB?

- How is your daily life?
- How is your routine in the health service?

The interviews were audio-recorded using a digital recorder.

To organize data, the Atlas Ti software, version 7.0, has been used. It is noteworthy that the software did not affect the choice of excerpts or the creation of discursive blocks, it only helped in data organization, whose choice and command were exclusive to the researchers.

Full interview transcripts were made, language vices in the respondents' speeches were corrected for a better understanding of the discourses. The discursive linguistic sequences were based on the DA approach, guided by 3 steps: first, from the linguistic surface to the discourse, built by successive readings of the fully transcribed interviews and by identifying the main ideas for reference excerpts to gather the discursive blocks; second, from the discursive object to the discursive formation, built by the discursive-linguistic sequences that play a significant role in the creation of meanings; and third, from the discursive process to the ideological formation, constituted in the return to sequences that constitute the analysis object, interconnecting the theoretical foundation of this study⁽¹²⁾.

In the presentation of discursive excerpts, the following codification has been used to represent the study subjects: S1, S2, S3, S4, S5, S6.

This study complied with the ethical principles of research involving human beings. The research project that gave rise to this article was submitted to the Brazil platform, being approved by the REC of the Federal University of São Carlos (UFSCar) on 11/06/2014, under the Opinion No. 860,668. The study participants have signed a free and informed consent form (FICF).

RESULTS AND DISCUSSION

Six people who met the inclusion criteria and voluntarily accepted to participate in the

research were interviewed, aged between 35 and 52 years, 5 men and 1 woman. Among the respondents, 3 reported having HIV for more than 10 years; 2 reported between 6 months and 2 years; and 1 discovered the diagnosis 8 years earlier. Considering the occurrence of TB, 3 cases were new, 2 re-treatments after dropout and 1 recurrence. The municipality where this study took place follows the protocol of the Ministry of Health so that the directly observed treatment (DOT) takes place, preferably in UBSs or in FHCs, close to the patient's home. During the data collection period, 5 respondents underwent DOT in primary health care (PHC) centers, but 1 was being monitored at the CAIC itself, as reported, due to his/her strong bond with that institution's practitioners.

For this study, 3 discursive blocks emerged, namely: "Tuberculosis and HIV: circulating meanings;" "The patient-practitioner bond and use of incentives in treatment continuity;" and "Conditions that influence the illness process." As discourse is an ongoing process and it is open to other interpretations⁽¹²⁾, it is noteworthy that the meanings produced in these discursive blocks are not watertight, therefore, they migrate from one block to another.

Tuberculosis and HIV: circulating meanings

In the first discursive block, we notice the circulating meanings when patients were asked how it was to receive the HIV and TB diagnosis. The discourses denounce the lack of knowledge on the part of people living with HIV about the risks of developing TB, as well as the poor understanding of the signs and symptoms of this disease and its rapid possibility of progression, due to a late diagnosis or difficulty in complying with treatment. Currently, there are still crystallized meanings that echo in the collective memory and in the discursive memory of those with co-infection, they refer to prejudice, stigma, belief in TB eradication, or their existence is restricted to urban agglomerations, such as tenements⁽¹⁵⁾. Such a set of meanings still imbedded in the human collective can result

from poor knowledge of the disease among respondents, which can often collaborate with difficulty in complying with treatment or even with the denial of it.

Also, it is necessary to think through the understanding of those who live with co-infection in the face of the HIV disease process when relating it to risk behaviors, such as unprotected sexual intercourse and the use of psychoactive drugs. This scenario produced, and still produces, in the collective imagination some stigmas and labels about these diseases that go beyond the borders of "a complex pathological phenomenon."

For me it was normal. I had lots of sexual partners and drug use; you know! I wasn't as shocked by HIV as I was by tuberculosis. (S4)

HIV [...] I don't have HIV! [Tuberculosis] is a serious issue. (S2)

[...] because HIV hasn't harmed me at all. But tuberculosis knocked me down. (S4)

At the beginning of the epidemic, the emergence of HIV/AIDS was associated with minority groups, whose behaviors were considered 'inappropriate' to social norms, such as the cases of homosexuals, sex workers, and users of psychoactive drugs. Subsequently, there was a change in the characterization of HIV patients, which persists until today, as infected people became heterosexual, with an increase in female cases and among those with low education⁽¹⁶⁾.

Thus, in this study, patient subjection in the discursive sequences has been noticed, i.e. the acceptance of a circulating ideology that is still exists in the social imagination that HIV infection is closely linked only to individuals affected by the virus in the early days of this disease, such as drug users. Such facts require debates and the building of strategies and actions, as well as new studies mediated by public policies, health practitioners, and researchers, regarding infection and prevention, aimed at all social classes and age groups, as well as both sexes, regardless of their sexual orientation, in order to break with this thought so deeply rooted in the social body.

In this block, the study subjects highlight the faces of living with such conditions, the

prejudice reproduced within support institutions (hostel, health care network, and social circle) after co-infection, being places where these people previously felt embraced, as the discursive excerpts emerge. In addition, family-related senses stand out as a major support in treatment continuity and in living/coping with TB and HIV, 2 chronic conditions that still face great social stigma.

It's been good, at the same time bad, you know. Because a lot of prejudice, a lot of prejudice [...]. Ah! I stay away from everyone [...] because many people have prejudice. (S5)

No, my family, thank God. My family is 100% normal. They never kept me [silence], they even tried to help me, my family. Always. I'm still alive today thanks to them. They never abandoned me. They never discriminated against me. And there are families that discriminate against the person. Want to see the person die because of these things. They don't support, discriminate against [...] don't help, don't make a juice [...] my mother comes repeatedly here with me, now I'm stronger, you know! I come alone. (S4)

I felt embraced, very protected by them all. To this day I have nothing to complain about because there was no discrimination at all. Everyone accepted well, helped a lot. There was no discrimination at all. (S6)

In relation to TB and HIV co-infection, stigma is regarded as one of the main hurdles in fighting both epidemics. Many do not reveal the diagnosis to their family members or social circle, for fear of having their identities exposed to the community to which they belong, and how this person will experience their illness process depends on the social bond established or not. It is noteworthy that the family, in this context, helps the person to move and adapt in a unique way in this path⁽¹⁷⁻¹⁸⁾. However, we notice in the speeches that lack of support or poor support significantly contributes to manifestations against the process of negative influence on treatment adherence.

Bonding and embracement: strategies for treatment continuity

The user-practitioner relationship

contributed to improving treatment adherence for both TB and HIV. In addition, it shows us that these individual feels embraced, cared for, and supported by the health service team to which she/he is linked, according to her/his idea or to her/his his 'meaning,' a unique subject in this health care scenario.

No, I'm not going to the health care center. I only undergo treatment here. Oh, they're cool with me. The woman over there... health worker X, they're nice to me. The doctor also cares about me. (S4)

There was a nurse there who was key, she was very strong, to the point of calling doctors who weren't even there. They did all this. (S3)

The discursive sequences highlight the importance of the constitution and dynamic monitoring of the multidisciplinary team in the health care network. The characters named as nurse, health worker X, and doctor provided assertive assistance to carry out actions aimed at the uniqueness of each individual. Also, it is noticed that S3 appreciates the nurse's movement and brings, in his/her interdiscourse, produced meanings of recognition and acknowledgment of all professional categories in the health sector, emphasizing the importance of interconnecting knowledge and actions between individuals in this field for treatment continuity and outcome.

A study highlights that in health care situations like, for instance, treatment of patients co-infected with TB and HIV, multidisciplinary teams and institutions are required to deploy systems that enable creative exchanges in the various knowledge areas, balance of powers, co-responsibility, self-organization, and autonomy of each individual involved, in order to seek quality care⁽¹⁹⁾. However, the author claims that this process is tough, as it involves the reformulation of institutional structures, values and habits enforced and sustained by the culture of modern society. Also, health teams face social, pedagogical, political, and ideological hurdles when pushed to change the reality of care⁽¹⁹⁾.

It has been identified that some respondents face both ease and difficulty regarding the issues of accessibility to health services and

the use of incentives for care continuity. Through the discursive sequences, it is noticed that the user, during treatment, needs to adapt to the health service's working hours, as well as to the available times of public transport or ambulance (which must be previously scheduled in the municipality). Nevertheless, it is necessary to ask for family and friends when access to existing resources, for instance, transport pass, is not available. These aspects also contribute to hinder compliance with both TB and HIV treatment.

I come with my car. My brother-in-law is bringing me. I also take the bus, which only takes me here, as it's early, it's a bit complicated for them. (S6)

Ah, the exams, too. Sometimes they give a transport pass, sometimes like this, but... I don't know if you can take someone's car to come, but sometimes I borrow it from my family, when I feel really bad. (S4)

Access to the health service is seen as a way to enter this health care facility and a means to analyze how this individual is cared for. This concept also refers to the barriers found along this path, which are legal, territorial, socioeconomic, or cultural, and they can help or hinder the relationship between users and the health care provided⁽²⁰⁾. The Brazilian National Tuberculosis Control Policy emphasizes that, in order to strengthen the DOTS (directly observed treatment – short course) strategy, it is necessary to decentralize TB control actions for PHC and, therefore, it is key to expand access to the general population, vulnerable populations, such as those co-infected with TB/HIV⁽²⁰⁾.

Thus, the discourses shown in this discursive block invite us to build/strengthen the bond between health service users and the multidisciplinary team. It becomes necessary to meet the needs and peculiarities of each individual, to build reintegration and social rehabilitation strategies and teamwork, in addition to public policies to incentive, such as basic food basket, transportation vouchers, which go together in the search for increased compliance with treatment and better quality of life among these individuals.

Conditions that influence the illness process

And, in the last discursive block, we notice, in the subjects' discourse, the dimension of the impact caused by such comorbidities, reaching not only the biological and physical aspects of these people, but also their emotional and psychosocial aspects. In this research, some respondents revealed that pain, along with a complex therapeutic scheme, is a hurdle to continuation their daily activities, negatively influencing the quality of life of these individuals. Thus, adverse reactions arising from the use of antiretroviral drugs and medicines for TB are directly related to compliance with treatment and in the future to the healing process, as noticed in the following excerpts:

Oh, I don't know now. My feet were numb. Foot pain, leg pain, I don't even know what it is. You know it was really bad. I still feel bad today. So, I feel bad, I've recovered, I've gained weight, I'm eating... what's left is fatigue and bone pains, things like that. The spirit, I've lost my spirit! (S4)

I fell into illness. It feels a little bad at first, but I got used to it, what could I do? I've had to get used. (S6)

I accept the medicines well, you know. I already know the medicines by heart. My foot was crooked because of this, because the doctor didn't know, the doctor [...] found out that it had tuberculosis ganglia and I was treating toxoplasmosis. Then the medicines didn't match each other and that's why I stayed in the wheelchair. (S6)

In this context, the DOT has become a challenge for government spheres and health institutions, as it is a long-term treatment, which can cause several adverse reactions, as described above. And because there is a correct time for it to be taken, there is an incompatibility between the working hours of health services and the working hours of some respondents. In this sense, TB/HIV co-infection generally affects economically active people who use psychoactive drugs and have irregular hours for eating and resting. That is, factors that contribute to treatment dropout in the early months or even to its interruption⁽²¹⁾.

And, finally, the discursive sequences highlight the poor TB diagnosis, which makes

us reflect on the need for proper clinical listening, comprehensive care, and also the objective and subjective weaknesses that surround such pathologies.

Thus, the search for respiratory symptoms to identify the disease sometimes falls short of the goal, as poor knowledge about TB signs and symptoms, as well as its transmission mode, diagnosis and treatment by professionals lead to significant consequences to health care and active search of new cases⁽²²⁾.

Some authors reinforce that professional qualification regarding TB management must take place through systematic and ongoing training and that all practitioners must be updated due to treatment complexity and intensity⁽²²⁾.

At this point, it is worth pointing out the need for planning and interconnected institutions, managers, and health workers, so that knowledge about TB is disseminated. The aim is providing the individual affected by TB with comprehensive care, which meets their needs and, consequently, leads to a successful treatment outcome⁽²²⁾.

The discourses about the illness process due to TB/HIV co-infection have produced meanings, which perpetuate until today, and show how these respondents experience this moment. In the case of TB, social vulnerability still exists, requiring debates, assertive strategies, deployment of public policies, and actions taken by health professionals regarding the disease and prevention aimed at all social classes, age groups, both sexes, regardless of their sexual orientation. It was possible to notice the poor knowledge of people undergoing treatment about these diseases, as well as their denial, due to the meanings crystallized in society, fear of being identified, and rejection of their social circle. The discourses also highlighted the family's importance in treatment continuity, minimizing distress due to diseases, and the need to include family members in the care and assistance provided to this individual.

Not withstanding, it must be remembered that discourse is something in constant motion and it is not finite; thus, this study is open to new interpretations and discussions on this major and overarching theme.

FINAL CONSIDERATIONS

(CON)VIVER COM TUBERCULOSE/HIV OS SENTIDOS REPRESENTADOS PELO PROCESSO DE ADOECIMENTO: UMA ANÁLISE DE DISCURSO

RESUMO

Objetivo: analisar os sentidos produzidos pelo processo de adoecimento e como eles afetam as pessoas que vivem com tuberculose (TB) e o vírus da imunodeficiência humana (*human immunodeficiency virus* [HIV]). **Método:** trata-se de pesquisa qualitativa, com fundamentação teórico-metodológica da Análise de Discurso (AD) de matriz francesa, realizada em um centro de referência para infecções crônicas, no período de janeiro a julho de 2015. Utilizou-se um roteiro de entrevista semiestruturada para a coleta de dados primários. Para a coleta de dados secundários se recorreu ao livro de registro e acompanhamento de tratamento dos casos de TB; ao Sistema de Informação de Agravos de Notificação (SINAN); e ao sistema de controle de pacientes com TB. **Resultados:** foram entrevistadas 6 pessoas que realizam tratamento para TB e HIV e emergiram 3 blocos discursivos: "Tuberculose e HIV: sentidos circulantes"; "O vínculo paciente-profissional e utilização de incentivos na continuidade do tratamento"; e "Condicionantes que influenciam o processo de adoecimento". **Considerações finais:** a concepção de que esses agravos acometem apenas determinados indivíduos se mantém circulante na sociedade, favorecendo o preconceito, diagnóstico tardio e dificuldade de adesão ao tratamento. Assim, fazem-se necessárias políticas públicas e ações de promoção à saúde por parte dos gestores e profissionais da saúde para contribuir com a (des)construção de saberes e o cuidado integral e longitudinal tanto daqueles que estão em tratamento quanto de seus familiares.

Palavras-chave: Coinfecção. HIV. Tuberculose. Saúde pública. Doença crônica.

(CON)VIVIR CON TB/VIH LOS SIGNIFICADOS REPRESENTADOS POR EL PROCESO DE ENFERMAD: UN ANÁLISIS DEL DISCURSO

RESUMEN

Objetivo: analisar os sentidos produzidos por el proceso de enfermedad y cómo estos afectan a las personas que viven con tuberculosis y VIH. **Método:** se trata de una investigación cualitativa, con fundamentación teórico-metodológica del Análisis del Discurso de matriz francesa, realizada en un centro de referencia para infecciones crónicas, en el período de enero a julio de 2015. Se utilizó un guion de entrevista semiestructurada para la recolección de datos primarios y, para la recolección de datos secundarios, se utilizó el libro de registro y acompañamiento del tratamiento de los casos de tuberculosis; el sistema de información de agravios de notificación y el sistema de control de pacientes con tuberculosis. **Resultados:** fueron entrevistadas seis personas que realizan tratamiento para Tuberculosis y VIH y surgieron tres bloques discursivos: "Tuberculosis y VIH: sentidos circulantes"; "El vínculo paciente-profesional y utilización de incentivos en la continuidad del tratamiento"; y "Condicionantes que influyen en el proceso de enfermedad". **Consideraciones finales:** la idea de que esos agravios afectan solo a determinados individuos, se mantiene propagando en la sociedad, favoreciendo el prejuicio, diagnóstico tardío y la dificultad a la adhesión al tratamiento. Así, se hacen necesarias políticas públicas y acciones de promoción a la salud, por parte de los gestores y profesionales de la salud, que contribuyan para la (des)construcción de saberes y promuevan el cuidado integral y longitudinal a los que están en tratamiento, así como a sus familiares.

Palabras clave: Coinfección. VIH. Tuberculosis. Salud Pública. Enfermedad Crónica.

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