DELAY IN THE DIAGNOSIS OF TUBERCULOSIS IN PRISONS: THE EXPERIENCE OF INCARCERATED PATIENTS

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ABSTRACT: This study analyzed the causes of delay in the diagnosis of tuberculosis in the prison system, according to the experience of incarcerated patients. The theoretical and methodological framework of the French school of discourse analysis was used, which seeks to comprehend the processes of meaning production, in the relationship of language with ideology and the development of subjects in their positions. Semi-directed interviews were conducted with seven incarcerated tuberculosis patients in a hospital in João Pessoa, Paraíba, Brazil, between August and October 2009. The delay in the diagnosis of tuberculosis was related to the naturalization of the lack of care for the prisoner, to the interpretation of the prison as a place of death and suffering and to the deprivation of the right to health for the detainees as a result of their position in the asymmetric power relationships and ideological effects.

DESCRIPTORS: Tuberculosis. Prisons. Diagnosis.

ATRASO NO DIAGNÓSTICO DA TUBERCULOSE EM SISTEMA PRISIONAL: A EXPERIÊNCIA DO DOENTE APENADO

RESUMO: O estudo analisou as causas de atraso no diagnóstico da tuberculose em sistema prisional, segundo a experiência do doente apenado. Utilizou-se o referencial teórico-metodológico da análise de discurso da matriz francesa, que busca compreender os processos de produção de sentidos, na relação da linguagem com a ideologia e de constituição de sujeitos em suas posições. Foram realizadas entrevistas semi-dirigidas com sete doentes de tuberculose apenados em um hospital de João Pessoa, Paraíba, Brasil, no período de agosto a outubro de 2009. O atraso no diagnóstico da tuberculose relaciona-se à naturalização da desassistência ao sujeito preso, à interpretação do presídio como um lugar de morte e sofrimentos e à privação do direito à saúde para detentos em decorrência de sua posição nas relações assimétricas de poder e efeitos ideológicos.


RETRASO EN EL DIAGNÓSTICO DE LA TUBERCULOSIS EN LA CÁRCEL: LA EXPERIENCIA DE LOS ENFERMOS RECLUSOS

RESUMEN: Este estudio analizó las causas del retraso en el diagnóstico de la tuberculosis en las cárceles, de acuerdo con la experiencia de los reclusos enfermos. Se utilizó el marco teórico y metodológico del análisis del discurso francesa, que busca comprender los procesos de producción de sentidos, en la relación del lenguaje con la ideología y del desarrollo de los sujetos en sus posiciones. Entrevistas semi-dirigidas fueron realizadas con 07 enfermos con tuberculosis reclusos en un hospital en João Pessoa, Paraíba, Brasil, entre agosto y octubre de 2009. El atraso en el diagnóstico de la tuberculosis estaba relacionado a que se entendía como natural la falta de atención al prisionero, a la interpretación de que la prisión es un lugar de muerte y sufrimiento y la privación de los derechos a la salud de los prisioneros como resultado de su posición en las relaciones asimétricas de poder e efectos ideológicos.

INTRODUCTION

The occurrence of tuberculosis (TB) in prisons, as a public health problem, presents significant magnitude. Studies on the health of the incarcerated population in Brazil, of which there are few,\(^1\) show that the increasing prison occupancy rate, without the concomitant investment in the physical infrastructure and human resources, combined with the precarious conditions of hygiene, ventilation and natural light in the cells, compose a frequent scenario in the prison system. This situation produces risks for inmates becoming sick and creates favorable conditions for infection by *Mycobacterium tuberculosis*, and the spread of TB.\(^1\)-\(^4\)

A systematic review regarding the incidence of TB in prisons, including twenty-three studies from different regions of the world, concluded that the transmission of TB in the prison population is higher than that related to the local general population.\(^5\) The prevalence of TB among prisoners may be up to fifty times higher than the national averages.\(^6\) In Europe, it is estimated that, on average, the proportion of TB among prisoners compared to TB in the general community is 15:01. The fact that prisons act as reservoirs for multidrug-resistant TB (MDR-TB) aggravates this problem.\(^6\)

The difficulties in the development of health-care activities in prisons, especially in the preventive field, are of diverse orders. Regarding the obstacles to TB control in these places, it is noted that there are social and psychological peculiarities related to the organization and operation of the prison institution, highlighting the underestimation of the disease symptoms, the inadequacy of the TB Control Program for the prison population and the difficulties of access to healthcare, arising from the prioritization of security, by the prison authorities, at the expense of health.\(^2\)

Considering that the prisons are important in the origin and transmission of TB,\(^7\) the importance is stressed of early diagnosis as a strategy for disease control in the prison population. Failures in this process involve losses - for the patient: clinical complications and drug resistance; for the community: exposure to the bacillus, and for the State: the management of a complex and onerous condition.\(^8\)

In the present study, a length of time greater than thirty days elapsed between the onset of signs and symptoms and the first medical consultation for the diagnosis is considered a delay in diagnosis of TB, attributed to the patient, based on categories presented in scientific productions.\(^9\)-\(^10\)

Contextualizing the problem of TB control in the prison system, and considering the conditions of production of the experience of becoming sick in prisons, this study aims to analyze the causes of delay in the diagnosis of TB in the prison system, according to the experience of the incarcerated patient.

From the observation of the gaps in scientific knowledge related to the topic, the present study shows that it is relevant to explore discourses circulating within the prison space linked to the health-disease process, to TB and to access to diagnosis, analyzing - according to the theoretical framework of the French school of Discourse Analysis (DA) - the linguistic materiality and the networks of meanings to which the TB patients, in the social position of detainees, are affiliated. Discourse Analysis studies the effects of meanings among the interlocutors and is supported by three areas of knowledge: Historical Materialism, being situated therein the theoretical concept of ideology; Linguistics, particularly with the notion of materiality of the significant, and Psychoanalysis, incorporating the Lacanian comprehension that the unconscious is structured like a language.

The appropriation of DA for this research is an innovative proposal that will allow new comprehension regarding the (re)production of institutionally legitimated discourses in prisons. This is a useful framework for analyzing how the causes of delay in the diagnosis of TB are invested with meaning for and by the subjects in the position of prisoners. The results may contribute to the debate of public policies geared toward the needs of this vulnerable population and to guide health practices and Nursing related to the care for patients with TB in the prison institution.

METHOD

Working with the relationships between the multiple discourses that permeate life in the prisons and with the processes of meaning, associated with the delay in the diagnosis of TB in the prison institution, this study is based on the theoretical framework of the French school of discourse analysis.\(^11\)-\(^13\)

The study was conducted in a hospital which is a reference for TB treatment in the state of Paraíba, Brazil. The study participants were...
seven incarcerated TB patient, hospitalized, over eighteen years of age, who reported having thirty or more days elapsed between the onset of signs/symptoms of the disease and the performance of the first consultation for the diagnosis. This last criterion is based on scientific studies that present a definition for the delay in the diagnosis of TB attributed to patient.9,10

Through access to the hospitalization information system, patients were identified who were in the position of prisoners, and consequently, the study sample was constituted by those who, during the data collection period, were being treated in the sector, met the sampling criteria cited and agreed to participate in the study.

For the data generation, semi-structured interviews14 were conducted and recorded in the period from August to October 2009. After full transcription of the interviews, they were organized into a database using the Atlas.ti version 6.0 software, through the creation of a Hermeneutic Unit. In the presentation of the statements, a coding system was used to ensure the anonymity of the study subjects.

The interviews were conducted in the wards under police escort and guided by the following questions: (1) What do you usually do when you get sick?; (2) What did you feel that made you seek the health service?; (3) Tell me what happened from the beginning of the disease until your first trip to the health service; and (4) Tell me about the way that you passed through the health services until you discovered that you had tuberculosis. In the analysis procedure,11 working with the inter-related description and interpretation, the opacity of the language, the manifestation of the ideology, the production of meanings and the constitution of the subjects historical-social gestures of interpretation are used.

From the premise that the enunciative mechanisms are discursive constructions with ideological effects, the construction of the analysis procedure was guided by the following passages (or steps):11
(1) Of the superficial language for the discourse; (2) Of the discursive object for the discursive formation; and (3) Of the discursive process for the ideological formation. As a result, there were two discursive blocks, which united correlated fragments of speech and situation, discursively related to the delay in the diagnosis of TB.

To develop this study, the ethical principles of research involving human subjects contained in the Helsinki Declaration and Resolution No. 196/96 and No. 251/97 of the National Health Council were observed. The project that gave rise to this study was approved by the Research Ethics Committee of the Center for Health Sciences of the Federal University of Paraíba, on December 17, 2008, under protocol number 0589.

RESULTS AND DISCUSSION

The analytical procedure consists of discursive sequences of reference,13 with highlights underlined, in two main blocks, which bring together related and interpenetrated discursive formations, namely: (1) TB in the prisons: imprisoned health; and (2) Delay in the diagnosis of TB: experiences of the incarcerated patient. All the study subjects were male and aged between 30 and 39 years. Regarding schooling, five prisoners had incomplete elementary education, one had incomplete high school education and one had no schooling.

Tuberculosis in the prisons: imprisoned health

If the experience of the illness is the social life (produced, internalized and reworked by the social subjects) that involves the actors of the universe of the disease,15 it is comprehended that the prison institutions, to produce a reducing atmosphere of behaviors qualified by the autonomy, imprint characteristics specific to the experiences of the incarcerated patient.

One study subject said: I look for care, a doctor, but where do I go? In the place that I am [prison] there is no care. It is only a place of suffering, of harassment. We are hungry, we suffer, we are tortured, we are beaten up; that is the prison, it is the worst place there is (S02). This report expresses an experience of anxiety, frustration, violence, deprivation and suffering. As a discursive event,12 he revealed institutional violence, including the various forms of symbolic violence sustained in the prisons. The surveillance, the control and the punishment in the prisons produce effects of meaning, related to repression and to control over the bodies of these subjects, their lives, their gestures of interpretation, their discourses.16 The lack of care and the lines of power and tension circulating in the prison environment produce, in the words of this subject, the meaning of interpretation of the prison as “the worst place there is.”

The situations of incarceration produce psychosocial characteristics that generate effects regarding the formation of the systems of represen
tation, linked to the life in prison and particularly to the event of illness, related to the valorization of the symptoms, the search for care, the use of medication, and in general, to the practices and concepts of health-disease.

One study participant reported the following: *what I think more is when I get well here [in the hospital], I’ll have to go back there [the prison] to spend some time and I pray a lot to God that this does not happen [...] because I will be among those who are sick there. Those same people that I left sick there, and there are many of them that are sick there, and I’ll have to go back and meet them again* (S04).

The network of meanings, to which the study subject is affiliated, is linguistically materialized through the significant words “there” and “here”. While the prison is identified as a permanent space for the production of physical and emotional illness, the hospital is interpreted as the place of well being, healing and care, although, both act with mechanisms of disciplinary power.

One subject said: *there is one cell which accommodates twelve prisoners. So, only in this cell everyone has this disease [TB]. The prison is full of tuberculosis* (S07).

One study, by analyzing the management of the TB control actions in municipalities in the state of São Paulo, Brazil, inserted in the context of this problem the disinterest of municipal managers in the policies and strategies of TB control. From this perspective, it is believed that the, ideologically sustained, lack of political visibility of the disease contributes to the incipient actions to combat TB in the prison population, considered a priority by the Ministry of Health.

The persistence of TB in prisons may, culturally, produce meanings related to the perception of the illness, through the space of socialization of the prisoners, affected or not by the disease. This comprehension was constructed by the discursive analysis of the following statements: *I think I caught it from the others. In the place where I am [prison] there are many sick people* (S04), highlighting the perception of TB transmission; *according to what I saw there, [prison] patients coming to the hospital to be treated, I already knew I had tuberculosis, because I saw the example of many sick people there* (S04), evidencing the interpretation of the sick individual for the identification of the disease. The discursive memory being updated in the experience and statements of these subjects is thus expressed. In the internality of the prison institution the inter-discourse circulates, which affects the perception and produces an opinion about the signs and symptoms of TB, the adequate place for treatment and the mode of transmission of the disease.

One study subject described his observations: *there are many [incarcerated TB patients], and because they have to come [to the hospital] a few at a time, there are many with the same disease as me there. Then you cannot come directly, You have to go when it is your turn, one by one, two by two, because there are many prisoners, there are more than a thousand prisoners or nearly a thousand* (S02).

It was identified that there is an outflow of the incarcerated TB patient for hospital treatment that seems to be established by perceptible regulations, however, not explained by the prisoner. The access of the incarcerated TB patients to the diagnosis and treatment of the disease is penetrated by the administration of meanings of the illness produced by the subjects of the prison institution.

In this space of battles, resistance, negotiation of meaning and lines of power, circulate inside and outside the prison institution, the statement of the prisoner that *I cannot be undisciplined, behave badly, but being sick you have to come, it is required, it is the judge’s order* (S02) expresses the strength of the sense of discipline (prohibition) in the prison system and, at the same time, the legitimacy of the role of the judicial power in the management of the gestures of interpretation, produced in the context of the regulation of the access of the incarcerated TB patient to healthcare.

The denouncement of the minimal conditions of treatment in the prison causes ethical and political questions to emerge related to the right to health of this population. In the prisons of various countries, health is still not considered a right of the prisoner, but a concession of the prison management.

Failures in the early diagnosis of TB can result in increases in the mortality rate of the disease and lead to the development of clinical emergencies, which increase the rate of hospitalization due to TB. One subject said: *[...] in reality, they only brought me here [hospital] because my case was serious and, if it were not so, I would be there until today, suffering with this disease* (S06). This statement presents an important aspect: the prioritization of access to TB treatment for the prisoner who present an worsened clinical condition. It should be noted that the prison administration values this clinical worsening in that, before this, there is a kind of deletion of the experience of the disease.
Considering the existing hierarchies in the prison unit, the circulating power relationships and the management of gestures of interpretation of the incarcerated TB patient. To endure the pain can translate the meaning of the strength required in the social space of the prison and the desired identity of the subject. To endure and at the same time to petition God seems to refer to a contradiction present in remaining silent about what one wants to say.

Considering the system of domination, the confrontations in the prison space and the consequences of production of the erasure of detained subjects, some intercession relationships are established. This is a meaning produced by the following statement: a nurse who is there in the prison had a word for me, told the director about my situation, then the director came up to me, saw my situation and sent me to hospital (S07). In this situation of silencing the rights of the prisoner sick with TB, the subject, recognized by the prisoner as a nurse, becomes the spokesman of the patient.

The asymmetries of power present there increasingly distance the incarcerated TB patient from protagonism in his health-disease process. It is perceived that the meanings attributed to being sick or not, as well as the regulation of the access to the diagnosis and treatment of TB, are administered by subjects who exercise the surveillance and discipline in the prison institutions or outside of it.

**Delay in the diagnosis of tuberculosis: experiences of the incarcerated patients**

Concerning the theme of the delay in the diagnosis of TB in the prison system, the diverse particularities that emerge from the relationships and the mode of organization of life in these institutions must be considered - analyzed in the previous discursive block.

The perception and denotation of TB as a physical and psychological discomfort, as well as the search for therapeutic resources, is always an interpretative process of the sick subject in relationships of social interaction. Therefore, personal and social dimensions, enmeshed in becoming sick from TB in prison units, are mobilized in symbolic systems, in which the intradiscourse and the interdiscourse participate.

An incarcerated TB patient stated: well, immediately we looked for some medication that would provide an immediate solution to the disease. But, if we do not know the diagnosis of the disease, we will...
not manage to buy the medicine for that, right? [...] if I take the medicine and if I do not see any, let’s say, improvement, then I have to seek other means that lead me to really identify what I’m feeling (S11). Another subject said: I try to get better, first, the faith, then if you have faith, you seek those words of comfort, that the Lord gives (S01).

The two linguistic facts generate meanings related to the interpretation, permeating the activation of self care strategies, which precede the entry of these subjects into the formal healthcare system.

Regarding the relationship between self-medication and the delay in the diagnosis of TB, a study conducted in Ethiopia revealed that the patients who initially visited non-formal healthcare services and those who had self-medicating had a longer delay for the diagnosis of TB, attributed to the patient, compared with those who went directly to the formal healthcare services.18

Considering the models of care for the diseases, it is emphasized that there is an intense and constant relationship between the biomedical activities and the practices of self care (mainly self-medication) - an articulation commonly ignored by Biomedicine. It happens that, on one hand medicine encourages self care, on the other, practices such as self-medication are strongly ignored, generating a paradoxical effect.19

Another study, carried out in southern Thailand, affirms - regarding the effect of the use of pharmacies on the delay in the diagnosis of TB - that the pharmacy was the most common site for the first visit of the patient after the onset of symptoms (43%); up to 12% of the patients who self-medicating and those who recalled details of this visit indicated that the medication recommended was cough suppressants, mucolytics, bronchodilators and antibiotics, however, none cited a recommendation of tuberculostatics.20

In the first report the immediacy in the search for symptomatic relief in the face of TB is also expressed as a striking characteristic. This meaning is related to the prevailing technocratic paradigm in the field of health sciences, according to which interventions with an emphasis on short-term results are privileged and describe a powerful motivational force, called the “technocratic imperative”.21

The statement […] if we do not know the diagnosis of the disease we are not going to manage provides a sense of overlapping of the medical knowledge, embodied in the diagnostic clarification, with the popular wisdom. The effects of meaning arising from the biomedical discourse center the medical action on the disease diagnosis, hyper-atrophying the diagnosis and generating processes of erasure and deindividuation of the patient subjects, increasingly seen as homogeneous units.22

Regarding the perception of illness due to TB and the search for diagnostic features, one subject said: at the beginning, I did not really know I was sick and that it was tuberculosis. Yeah, I was curious to know what it was, you know? And from the moment that I started getting worse and worse I tried to find out. It was there in the prison, I talked to the doctor and the doctor also could not explain what it was. Then I spent three days coughing up blood, they took me here, brought me to the hospital. It was when I got here that I was diagnosed with tuberculosis (S06).

As a discursive event, the search for medical care motivated by the perception of a serious clinical state can be grounded in discursive formations updated in the incorporation of the technocratic model, which gives prominence to curative medicine.23 The meanings present there would be colonized by an eminently economistic logic, expressed in the high consumption of machinery, equipment and instruments, used as the main resources of diagnosis and therapy.23

Producing landslides of meanings from the “obvious” idea that the diagnosis of TB in prisons is easier, because all the prisoners are within easy “reach” of the health interventions, comprehends that there are multiple obstacles for the detection of cases of the disease in the prison system. The undervaluation of signs/symptoms of TB in a violent environment, where the concern for survival is a priority can be especially noted. Additionally, the risk of stigmatization and segregation are present, considering the importance of the protection generated by group membership and the weakness resulting from the recognition of the disease in an environment where the image of strength is fundamental.2

In the previous report, hemoptysis, as externalized evidence of a serious clinical state, functions as a prioritization factor, used by the prison authorities for the access of the incarcerated TB patient to hospital healthcare. It was also registered that the healthcare professional, who attends this patient in the prison, does not develop an adequate clinical investigation. The combination of these factors is potentially favorable for the occurrence of the delay in the diagnosis of TB, as well as for an increased risk of death from the disease.
Authors affirm that the delay in the diagnosis of TB attributable to the physician can show the level of knowledge about the disease among healthcare professionals and the efficacy of the TB Control Program regarding early diagnosis. In relation to the inadequate management of the disease and the disqualification of the interaction between the healthcare professional and the patient for the effectiveness of the diagnosis of TB, it is comprehended that it is important, in the prison system, to invest in hiring qualified human resources, in the development of the active search for respiratory symptomatics, in the prevention and treatment of comorbidities, in the implementation of Directly Observed Treatment (DOT) for TB, as well as in other actions related to health surveillance.

One study subject said: it was not a clinic. It was a hospital. Some doctors I went to twice, three times, four times, they said ‘ah, this is a cold. This is a headache’, they always gave a prescription, an injection and sent me away, headed for the prison and I was getting weaker [...]. the examinations [for the diagnosis of TB] that I did, all, all, none have arrived for me to see [...]. They just said [the physicians] ‘you are not well’, ‘you are not better’, ‘go back, go to the prison’. When I arrived in the prison, I was sick again. Each day that passed, I got worse, I returned to the hospital. The doctor said again [...] ‘you don’t have any problem’ (S01).

This denial of the experience of the illness of the prisoner subject is another form of this erasure present in an institution of surveillance, control and confrontation of forces. An expressive sense of subordination of the recognition of the disease to the medical knowledge is found in this linguistic fact. In the prison there are no processes of empowerment of the incarcerated TB patient in order to develop their protagonism in the development of the therapeutic project.

Concerning the healthcare of patients with TB in the prisons, one subject said: [...] he [the physician] gives you medicines that are not right, tablets. There is no correct medicine for Tuberculosis in prison, first for you to take these pills you have to go to the doctor and there they gave me dipyrone, Anadot®, a lot of anti-inflammatories [...]. But when I came to do the examinations, the results showed consciously the tuberculosis (S05).

This report expresses weaknesses in the care for the incarcerated TB patient regarding issues of diagnosis. The conformation used by the physician concerning the patient reveals the meaning of power-knowledge that biomedicine, socially legitimated, holds and manages, using to produce increasing medicalization of the human life and of the relationships of subjection inscribed in specific historical and discursive formations.

The statement there is no correct medicine for Tuberculosis in prison expresses the inadequacy of the treatment within the prison system - a gesture of interpretation reinforced by the subject, when he affirms that, after the performance of the examinations outside the prison, the TB was diagnosed adequately and, in the statements of the subject, “consciously”. Thus, the subject of the study did not identify the prison as the place of the “conscious” diagnosis of the TB.

The difficulties for the incarcerated TB patient to have access to the diagnosis and treatment of the disease are of diverse orders. One subject said: I asked the director if I could come to the hospital. But it was a struggle. I spent more than six months asking before managing to come [to the hospital] [...] [after having carried out the examinations] I went back there again. Then for me to manage to return here it was another struggle. I was another three months asking (S04). Another said: [...] I came to get treatment now, after five months (S05). Another subject also expressed the difficulties faced: [...] it was difficult to get here [hospital], because as I was very sick, they claimed they had no vehicle, claimed that they had no guard to stay here with me (S07).

In this context, it can be perceived that the discursive formations, which circulate in the imagination of the people linked to the social life in the prisons, are permeated by meanings related to a high burden of difficulties, suffering and punishment for the prisoner.

In this universe, where the speech of the detainee is restricted, considering the social position he occupies, care relationships are mobilized, involving other actors and roles. One subject of the study talked about this issue: the same day that I vomited blood I went straight to the gate of the prison, called the guard and told him: guard I’m sick because I’m vomiting blood. Then he took me to the director (S03). Another said: I was obliged to report my situation to the guards, to the nurse, to the others who were with me in the cell block, to say I was sick. To report my situation (S07). Another subject said: the nurse of the prison, is not even a nurse, he is a prisoner, like me. He was one that liked to read (S02).

The causes of delay in the diagnosis of TB in the prison system are diverse, however, all contextualized in the experience of the illness in a disciplinary institution of reduced autonomy, as well as in discursive formations that define roles.
(according to social construction) and motivate views about the subjects inside the prison network. The work of putting the spoken in relation to the unspoken of the incarcerated TB patients is very revealing for a deep comprehension of the problem addressed here.

**CONCLUSION**

The analytical procedure of the study highlights the conditions of production of the spoken (and unspoken) of the incarcerated TB patient with regard to the causes of delay in the diagnosis of TB. When contextualizing these factors in discursive formations circulating in the social space, with reference to the prison institution, a displacement of the identification for the comprehension of these causes is undertaken.

The study subjects are deprived, through regulations, of the constitutional right to health and, in the prison units, processes of subjection are constantly produced in the experiential quotidian of the incarcerated TB patients.

The punishment and surveillance in the prisons generate feelings of repression and discipline regarding the linguistic materiality of the incarcerated TB patient. The prison is identified as a place of death, sufferings, and worries. The hospital, in turn, has the representation of a place of life, health, and care attributed to it.

The regulatory process of the access of the incarcerated TB patient to the care practices for the diagnosis of the disease reveals lines of power and management of the gestures of interpretation within the social reality of the prisons.

The study argues that health, as a right of ethical-humane care and of citizenship, while symbolically imprisoned, produces the scenario in which the diverse causes of delay in the diagnosis of TB are consolidated.

Considering the diagnostic actions of TB in prisons, the study suggests improvements in the actions of the search for respiratory symptomatics that make the early diagnosis of TB in prisons possible, especially regarding their continuity, in addition to improving the quality of the healthcare in prisons and the articulation with other services of the healthcare network.

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Received: March 15, 2011
Approved: November 30, 2011


