ACCESS TO DIAGNOSIS AND TREATMENT OF MULTI-RESISTANT TUBERCULOSIS: DISCURSIVE ANALYSIS

ACESSO AO DIAGNÓSTICO E TRATAMENTO DA TUBERCULOSE MULTIRRESISTENTE: ANÁLISE DISCURSIVA

ACCESO AL DIAGNÓSTICO Y AL TRATAMIENTO DE LA TUBERCULOSIS MULTIRRESISTENTE: ANÁLISIS DISCURSIVO

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ABSTRACT

Objective: to discursively analyze how multidrug-resistant tuberculosis patients experience the process of diagnosis and treatment of the disease, identifying possible difficulties and potentialities, as well as nursing practice. Method: this is a qualitative, descriptive study of patients undergoing treatment at two reference institutions. Semi-structured interviews were conducted and analyzed according to the Discourse Analysis framework, French matrix. Results: two discursive blocks were pointed out: “Access to the diagnosis of multidrug-resistant tuberculosis” and “Access to specific treatment”, both under the nurse’s role. Conclusion: it is considered necessary a differentiated look of health professionals for the diagnosis and treatment of multidrug-resistant tuberculosis so that the organization of services is not a barrier to disease control. Descriptors: Tuberculosis, Multidrug-Resistant; Health Services Accessibility; Universal Access to Health Care Services; Directly Observed Therapy; Qualitative Research; Address.

RESUMO

Objetivo: analisar discursivamente como os doentes de tuberculose multirresistente vivenciam o processo de diagnóstico e tratamento da doença, identificando as possíveis dificuldades e potencialidades, bem como a atuação da enfermagem. Método: trata-se de um estudo qualitativo, descritivo, com doentes em tratamento em duas instituições de referência. Realizaram-se entrevistas semiestruturadas e analisadas de acordo com o referencial da Análise do Discurso, matriz francesa. Resultados: apontaram-se dois blocos discursivos: “Acesso ao diagnóstico da tuberculose multirresistente” e “Acesso ao tratamento específico”, ambos sob a atuação do enfermeiro. Conclusão: considera-se necessário um olhar diferenciado dos profissionais de saúde para o diagnóstico e o tratamento da tuberculose multirresistente para que a organização dos serviços não seja uma barreira para o controle da doença. Descriptores: Tuberculose Resistente a Múltiplos Medicamentos; Acesso aos Serviços de Saúde; Acesso Universal a Serviços de Saúde; Terapia Diretamente Observada; Pesquisa Qualitativa; Discurso.

RESUMEN

Objetivo: analizar discursivamente cómo los pacientes con tuberculosis multirresistente experimentan el proceso de diagnóstico y tratamiento de la enfermedad, identificando posibles dificultades y potencialidades, así como la práctica de enfermería. Método: este es un estudio cualitativo, descriptivo de pacientes sometidos a tratamiento en dos instituciones de referencia. Se realizaron entrevistas semiestructuradas y se analizaron de acuerdo con el marco de Análisis del Discurso, matriz francesa. Resultados: se señalaron dos bloques discursivos: “Aceso al diagnóstico de tuberculosis multirresistente” y “Acesso a tratamiento específico”, ambos bajo la actuación del enfermero. Conclusión: se considera necesario una mirada diferenciada de los profesionales de la salud para el diagnóstico y tratamiento de la tuberculosis multirresistente a fin de que la organización de los servicios no sea una barrera para el control de la enfermedad. Descriptores: Tuberculose Resistente a Múltiplos Medicamentos; Accesibilidad a los Servicios de Salud; Acceso Universal a Servicios de Salud; Terapia por Observación Directa; Investigación Cualitativa; Discurso.


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INTRODUCTION

Despite substantial progress in the prevention, diagnosis and treatment of tuberculosis (TB) in recent decades, it is known that through effective public health actions, political commitment and resource mobilization, there is still wide inequality in access to health care related to this disease, because thousands of people suffer from the ills that it causes worldwide. It is noteworthy that, despite the fact that diagnosis and treatment are free of charge in over 87% of the countries in the world, 4 the need to overcome existing obstacles that prevent patients from accessing them is free.

It is reported that social, cultural, demographic and organizational barriers are related to non-adherence to treatment consequently contribute to the increase in cases of multidrug-resistant tuberculosis (MDR-TB) and extensively resistant or over-resistant tuberculosis (TBXDR).

MDR-TB is characterized by loss of susceptibility to isoniazid and rifampicin, and its extension, TBXDR, by increased resistance to fluoroquinolone and a second-line injectable, which is considered a threat to disease control in world level, giving that treatment is highly complex, expensive, more toxic and generally less effective than traditional (sensitive TB), increasing the proportion of deaths.

The gap in TB access and coverage is proportionally larger for multidrug-resistant cases, as there are other factors, such as low coverage of drug susceptibility testing, insufficient access to second-line drugs, inadequate drug capacity care system for these patients and treatment and follow-up by different health services.

It is argued that nurses play a leading role in the prevention and control of TB (sensitive or multi-resistant), because, besides being the professional who is in direct contact with the patient, is present in all phases of disease control activities, either in an outpatient or hospital setting.

This study focuses on the organization of services as a barrier to access to diagnosis and treatment of patients with MDR-TB and TBXDR. Studying the accessibility of diagnosis and treatment, based on the experiences of these patients, is important to understand, through those who are directly affected, which organizational barriers make early diagnosis and subsequent treatment difficult, since they favor the spread of resistant cases, which presently pose the greatest threat to disease control.

METHOD

This is a qualitative, descriptive study, developed in two locations, a referral outpatient clinic (OC) and a referral hospital (RH), both located in the interior of São Paulo, in order to understand the broad aspects involving the access to diagnosis and treatment of MDR-TB.

Regarding the assistance to MDR-TB in the State of São Paulo, there are two referral hospitals for long-term hospitalization and nine outpatient referral centers for treatment. Among these, the OC and RH were selected, because, despite being located in different municipalities, they are responsible for the care of patients in similar areas. OC is one of the nine outpatient referral centers for the treatment of MDR-TB in São Paulo state, being responsible for monthly medical consultations, case monitoring and drug supply, as well as articulation with Primary Health Care (PHC), which in turn accounts for the directly observed treatment (DOT), while RH is one of the State Secretariat's institutions for long-term TB hospitalizations, where patients receive all inpatient treatment.

Initially, the experiences of patients treated in the OC were analyzed, however, from the data obtained, it was observed the need to understand how they faced long-term hospitalization, thus aiming at a broader understanding of access to diagnosis and treatment of the disease.

It is noteworthy that the study participants were over 18 years old, with no diagnosed cognitive problems and were outside the prison system. In both scenarios, the inclusion criteria covered individuals undergoing treatment for at least six months and, upon guidance on the study objectives, agreed to sign the Free and Informed Consent Term (FICT). Thus, 21 participants were selected for convenience. However, five were excluded, four from the OC - three from very distant municipalities that were difficult to contact during outpatient consultations and one who refused to participate - and one from RH, who was discharged during the data production phase.

Data was collected between March and May 2012, in OC, and from April to June 2014, in RH. To this end, the first two authors (both properly trained and without any involvement with the institutions or patients) performed semi-structured interviews with each participant, individually and in a single meeting, lasting approximately 40 minutes. in the RH, OC environment or at home of the subjects undergoing outpatient treatment (four participants), being recorded by means of a digital recorder. This type of interview was chosen because it allows a certain direction in the

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researcher-subject relationship, thus ensuring the fulfillment of the proposed objectives. A script was developed for the production of data, which was composed of open guiding questions in order to understand the course of participants by different health services in search of establishing specific treatment, including items such as the identification of resistance, sensitivity to specific drugs and the establishment of effective therapy, as well as case follow-up for good prognosis.

The interviews were transcribed and the information organized in the Atlas.ti software, version 7.0. For the analysis of the data produced, we opted for the theoretical-methodological framework of Discourse Analysis (DA), of French matrix, in order to work with the understanding and production of the meanings of the speech of MDR-TB patients.

The study project was approved by the Ethics Committee of the University of São Paulo at Ribeirão Preto College of Nursing, under number 569063, thus complying with Resolution No. 466/2012 of the National Health Council (NHC). RESULTS

There were 16 participants in the study, 12 men and four women, aged 24 to 67 years, and an average of 41.7 years. These were identified for the presentation of the results and protection of anonymity of the participants, with a letter (P) and a number, being the first eight patients treated in OC and, from the ninth, those undergoing treatment in RH.

Regarding the classification of cases, 13 were affected by MDR-TB, while three suffered from TBXDR (all hospitalized). Most participants had previous TB treatments - ranging from one to five drug regimens for the disease, with only two (P5 and P15) in their first treatment.

The analysis was supported by two discursive blocks: “Access to the diagnosis of MDR-TB” and “Access to specific treatment”, with nursing contributions and participation being a cross-cutting theme. The following are excerpts from the subjects’ discourses and the analysis of the empirical material produced in the interviews under the discursive approach.

Access to MDR-TB diagnosis

It is understood that, in both study scenarios, patients presented similar trajectories until the confirmation of resistance diagnosis, marked by the combination of the history of treatment for TB with the basic drug regimen and the suspicion of resistance.

It can be noted in the excerpts of the participants’ speeches aspects related to these questions, which are presented below.

First, I was taking the medicine at home, the little post took the medicine, every thirty days, took me the medicine, then it did not work, started with RIPE, right, which is the base medicine that begins. (P10)

My medicine has always been supervised. I've always had to take with someone from the social worker, a nurse, so much so that until today I have a standard nurse and a nurse up here, and they control my medicine. (P1)

I had to treat at home, only I couldn't take the medicine; it's not that I couldn't, I didn't take it. (P12)

Other elements resulting from the long process of living with the disease are found, such as the absence of improvement after the use of the prescribed medication.

It's just that after the treatment I came back [...]. I stayed in bed, I didn't walk, I didn't walk. Until he shaved, he shaved on the floor. The drugs had no effect, where I was transferred to RH. (P4)

Then, he did the exams again, then the nurses said, “You're good for the doctor here.” Because he wasn't from that area there, it's in the little post. The doctor looked over there and said, “You’re new.” And already sent me away. [...] but, I was still feeling the same thing, fever, that sweat [...]. Then, the girl [daughter] arrived, saw that situation [...], she said: “Dad, let's pay a private doctor, let's take you”. Then it took. The doctor arrived there: "I'll move on to a specialist doctor who works with me." He told me to take the exams; When he saw the exams, he said, "Hey, you [P2], the only solution is to go to the AR." Then, he sent it to me, I came here. (P2)

Then, but it happened, then they didn't solve anything, I went to the post, but you know what the post is like, they don't solve much, they don't take it seriously, I think now it's being taken more seriously than rather tuberculosis even more multidrug resistant. (P9)

Access to specific treatment

It is also verified that the diagnosis of MDR-TB presents similar aspects between the two study scenarios, that the treatment presents elements of great differentiation related to the places and the structure of the services that perform it, as far as the own access to the service for treatment regarding the most particular aspects of the organization and implementation of care and also in relation to the activities performed by nursing professionals.

I was about three to four months waiting for this vacancy, more or less there, that's what worked out here, right, then, I came here. (P13)

It is observed that some patients, even with the indication of hospitalization, may have resistance to enter the hospital environment.

The nurses there, the bosses there, I joked, because I didn't want to be hospitalized, so, I said: "Oh, if this disease is there, I will, because I have my family at home" So that's where they set up this clinic here, and I came here. (P16)

This I no longer know, whether or not there is [communication between the OC and the PHC],

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but the person responsible for the request, being worried about me doing the tests and taking the medicines, is the nurse at the health center. (P1)

It can be noted, as each patient comes from a different municipality, a different organization for the provision of services.

At first, they [PHC nurses] would call the woman there: "How are you, Mr. P2? [...] at the beginning, too, when I came here to the OC [...]. Then, he changed his head, his head nurse [...]. The new one came a couple of times and then said you couldn't go anymore because you couldn't afford it, she didn't have a car, the city wasn't giving her a car to go. (P2)

It was found that, in the hospital environment, the care process occurs differently from PHC, since, in this scenario, the control of drug intake is a routine activity that is independent of negotiations and a differentiated structure; Thus, nursing has other aspects.

Yeah, their system here is a little complicated, it's a little rule from here, a little rule from there, which, in my view, there is no need, but it has to be, right? [...] these days I had a fight with them [Nursing staff] because my family, when they come, bring things to me, like cookies, these things, shampoo, conditioner, soaps, these things, right, not to be totally depending on the hospital [...] there, they wanted to take [...]. Because there is logic, there are patients who have problems with alcoholism, drugs, so that is why they restrict [...]. I don't drink, I don't use drugs [...], so they claim that, like, I can't have money, we can't have money. (P11)

**DISCUSSION**

It is noteworthy that the ages are in agreement with the results found in the National Survey. This fact reinforces the social and economic importance of the disease, as it affects many people of working age.

Another fact that deserves attention in the participants’ profile is that the most severe cases of resistance are being hospitalized and, although this is not a recommendation linked to the TBXDR profile, the possibility is admitted. treatment of patients with more difficult therapy.

They are in the speech of P10, first excerpt presenting some meanings that should be highlighted: firstly, the participant reveals the meanings of illness and treatment evidenced by the presence of the linguistic mark “postinho”, which establish, in relation to this patient, a routine follow-up of the case in PHC, that is, the enunciation of this subject, according to his ideological position (the socio-historical and ideological aspects that he experienced), is perceived in his speech. It is estimated that the subjects occupy certain positions while pronouncing their words and they unveil assumed socio-ideological places, that is, with regard to the occupied places, the senses are produced.

However, the most significant aspect refers to the use of the acronym “RIPE”, which designates the four main drugs used in the intensive phase of treatment of MDR-TB (rifampicin, isoniazid, pyrazinamide and ethambutol). When using this linguistic resource, P10 makes use of a discursive formation (DF) belonging to a different symbolic universe, approaching the health discourse. DF is understood to mean what, in a given ideological formation, considering its socio-historical context, determines what may or may not be said. Thus, it is pointed out that this concept implies the existence of a certain meaning, produced due to its insertion in a DF and not in another, starting to assume a meaning and not another, from who speaks and in certain production conditions. Thus, when the subject uses the term “RIPE”, he mobilizes an arsenal of meanings that, despite being proper to health professionals, have a different meaning for him, or even interpreted and resignified, translating the medical discourse of treatment effectiveness and effectiveness into a language more palatable to the patient - “the foundation that begins”.

On the other hand, it is found that the familiarity and appropriation of this symbolic universe reflect the long living with the disease. It is known that, like most subjects investigated, P10 was not in his first treatment for TB, but had already gone through one, which was discharged due to bankruptcy, even with part of the treatment being performed in the hospital environment due to social reasons that prevented adherence, such as alcoholism. This is an unemployed 39-year-old single mason with no children who had been undergoing specific treatment for MDR-TB for 23 months at the time of the interview. It is noteworthy that the patient has a long history with the disease and the speeches that are characteristic of it. The role of previous poor treatment in the development of resistance is highlighted, being the main risk factor for MDR-TB in several contexts, including in Brazil.

In this space of treatment for sensitive TB, in which the development and diagnosis of resistant forms are inserted, it is verified that the presence of nurses is a constant, especially in the conduction of DOT, both in the home environment and in the health units, as can be seen in the discursive fragment brought by P1.

In the speech of P12, it is noted that the patient assumes his difficulty in being responsible for his illness process, which is related to his current disease, i.e., MDR-TB. In addition, regarding the subject's production conditions (the socio-historical context), he has already undergone three previous treatments for TB, with the performance of DOT. However, due to the
abandonment, it was not possible to finish the established drug regimens, which led to the need for hospitalization and, in its history, there are two other hospitalizations in RH, which left without finalizing drug therapy. Proposal. This adds up to 15 months of hospitalization imposed due to judicial intervention.

It is understood that, with the linguistic marks “only I could not take the medicines”, the subject shows meanings prior to his current treatment, that is, there are traces of the number one forgetting. It is defined in AD that forgetting number one (also called ideological forgetting), characterized by the imminence of the unconscious, results in susceptibility to ideology, since, by forgetting the unconscious and ideology, the subject perceives things as see them. It is understood that, in this forgetfulness, the subject has the illusion of being the origin of his saying, but, in reality, the same retakes existing meanings. Thus, by the production of meanings of this subject, aspects of treatment abandonment.

Although P4 was interviewed in the OC, where he had been under follow-up for six months, this patient experienced hospitalization in a specialized hospital, RH. The complementarity between the two attention and research scenarios is evident. It is also possible to understand, through linguistic marks, the conditions of production, which constitute the verbal instance of discourse production, that is, the whole process that involves the socio-historical context, the interlocutors, the where they speak, their image of themselves, the other and the referent.

On the other hand, it is understood that the two subjects, P2 and P9, mean, in these discursive cuts, the peculiarities of access to the diagnosis of MDR-TB. It is noteworthy that the Unified Health System (UHS) guarantees the diagnosis and treatment of TB in its service network without the need for direct disbursement.

It is noted, however, that P2 refers to the need for consultations outside the public system, demonstrating that the search for the private is related to a silence on what is expected by local health services, especially the UHS and PHC. It is pointed out that silencing in AD is a necessary indentation so that it can mean, that is, the unsaid that exists in words, opening the space for the production of meanings. In addition, in the case of P2, the expectation that the private network will be able to solve their health problem is also not effective in the first attempt. At this point, it is indicated that its history resembles that of P9, as there is a need for the specialist symbolized by the reference centers for MDR-TB - OC and RH. Thus, there is evidence that access to the diagnosis of resistance and the initiation of effective therapy is related to access to tertiary care services.

It is understood that this factor is due to the need for two important laboratory procedures: sputum culture and drug susceptibility testing to determine resistance as well as the effective drug regimen to be used. As these two exams are not routinely performed for all TB patients, they can be presented as one of the signs of the relationship with access to tertiary service and, especially, to the specialist.

Situations like these make it possible to construct, in the collective imagination, the idea that PHC is unable to meet the demands of the resolutely population - “you know what the job is like”. It is argued that, here, the patient tries to mobilize, in the interlocutor, a justification that goes beyond his ability to express himself and, at that moment, elevates his speech to the plane of forgetting number two, in which the subject forgets that his words can be said differently. Thus, the patient, inserted in the only way he believes he can perform PHC, forgets that his health problem is serious and that he needs other mechanisms to make the diagnosis, such as professionals with differentiated training, so that the suspicion of resistance occurs, besides the adequate technological resources.

Moreover, in both discourses, the devaluation of the symptoms and feelings of the patients by the professionals who assist them is observed. These meanings are configured as an opposition to the treatment received, because even when the linguistic marks mean (“I was still feeling the same thing”), there is a verbalization of the health professional (“you are new”). It is important to highlight that it is in these mismatches, between the knowledge established, consolidated and permeated by the hegemonic discourse, that processes are broken, that the gaps are created so that the production conditions for the disease due to MDR-TB increase. The epidemiological and social importance of the difficulty in accessing the diagnosis of resistance is also emphasized, given the increased spread of resistant bacilli.

In this sense, the nurse does not seem to be sensitized to receive the patient’s complaints, since he only provides information. It is considered, however, that there is a silencing of its real posture, because the statement about the good state of health of the subject is not absolute, being conditioned to the individual appreciation of the doctor of the local service, as evidenced by the discursive mark “by this doctor”. Therefore, it is identified, again, the need for professional specialization for the diagnosis of multidrug resistance. However, it is noteworthy that, even though the diagnosis did not occur in the PHC space, it is possible to infer about the ability to resolve this situation, as the doctor performed the referrals, ensuring the continuity of care.

It is noticeable that although patients in both regimens identify very similar aspects, the

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differences in treatment are large. It is noted, by language marks, that the hospital environment has a limited number of beds, totaling 12 wards for individual care in the HR. It is known that patients with MDR-TB who need long-term inpatient treatment remain hospitalized for at least two years. Thus, in addition to the limitation of vacancies, there is a slow turnover of beds, which may be related to the long wait for hospitalization coupled with the scarcity of health services in the state of São Paulo that perform this type of assistance.10

The limitation of the number of beds is justified by the preference for outpatient treatment over the hospital. Thus, hospitalization is indicated in specific cases, such as severe manifestations, drug intolerance and co-infection with other diseases, in addition to cases of TBDR and cases in which outpatient treatment is impossible.9

It is clear from P16’s speech that his desire was not to perform hospitalized treatment. It is noteworthy that when P16 reports the need to be sought and persuaded by the Nursing team to go to RH, it silences an important aspect, probably related to his escape after receiving the news of the need for hospitalization; After all, it was only necessary to "hunt" him for fleeing. Another important silencing refers to the arguments used by professionals to persuade him: the need for family protection due to the possibility of contagion by the spread of resistant bacilli.

It is observed that, again, the speech of P1, following in RA, and its treatment shared with the PHC responsible for performing DOT, draws attention. Through his speech, the presence of nurses in the DOT is consolidated, and the linguistic mark “same” reinforces this idea present in P1’s speech. It is noteworthy that, besides being responsible for conducting an important tool to ensure adherence to treatment, this nurse supervised the performance of examinations, medication intake and transportation to the OC. However, it is pointed out by a study carried out in Lima, Peru, for even broader possibilities of acting in this professional category, mainly offering psychosocial support to MDR-TB patients.21

It is verified, in the analysis of the clipping brought by P2 about conducting his treatment at home, that the subject relates the efforts of PHC in the performance of DOT to the professionals who assist him, referring to the idea that the quality of care comes from personal efforts of health workers and not a set of norms and protocols that guide the work. It is argued that to say that “when the head nurse changed” there was a discontinuation of follow-up is to state that the current professional has other priorities that do not include verifying adherence to the instituted therapy. This subject is said to be “office center”, that is, under his words, others are said.12

This idea is opposed to the need of the patient in relation to the creation of strategies that guarantee the success of the treatment, since it is a person with a history of three other TB disorders, before confirming resistance, a fact that is worrying, considering the identification of DOT as an important strategy for the maintenance of the treatment, and should preferably be performed by a trained, sensitized health professional with adequate profile.21

It is noteworthy that patient P2 is a resident of the rural area, which justifies the difficulty of monitoring. It is known that the first nurse mentioned makes telephone contacts to obtain information about medication intake and, although this is not the most advisable type of supervision for MDR-TB, there is some effort to follow up the case. At the moment, the new professional tries to get closer and then gives up, because she does not have an infrastructure to support this task (although there are no reports of alternative attempts). This situation can also contribute to the creation of escape lines and the consequent abandonment of drug treatment.

However, it is clear from P11’s speech that, in general, hospital care is marked by the standardization of conduct and routines that range from behavior in the collective to the care of one’s own body, such as the time determined for the treatment. the bath, the food and all the other “rules” that the hospital service contemplates in its structure. It is understood that this way of controlling the dynamics of life of patients undergoing treatment in these services can cause feelings of self-esteem in the involved subjects, in addition to the removal of daily activities and family life. Another factor expressed by the patients is the fact that they become dependent on health professionals, losing their autonomy, especially hygiene and feeding routines.22 Thus, P11 is claimed by the need to be seen individually by the RH Nursing team and not in the group of patients hospitalized there and, in a way, that these rules and routines become more flexible, making treatment in the hospital a less suffered path.

It is understood that the discursive fragment of the subject reveals the current sayings and those that lodge in memory, that is, it mobilizes discourses determined by what has already been said in an articulation of discursive formations dominated by interdiscourse, which is constituted as (discursive) memory. affected by forgetfulness. On the other hand, the intradiscourse is the materiality of speech: what is being said at that moment. These senses are mobilized when the “regrinha” and “fought with them” language marks are articulated.

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CONCLUSION

It is concluded that the subjects affected by MDR-TB are involved in a complex symbolic universe permeated by the approach to various health services. It is known that these individuals bring meanings from a long history of coping with the disease, which begins since the treatment of the sensitive form (for more than one involvement).

It is pointed out that access to the diagnosis of resistance, however, is also a very difficult task, as it requires a differentiated look from professionals and seems to be related to the need for specialization. Thus, access to the tertiary level of care is related, either at the outpatient clinic or at the referral hospital. Discussing access to treatment encompasses issues such as admission to services and individual patient demand. Thus, it is evaluated that, for those who need hospitalization, this path can be more time consuming and harmful, not only to the patient, but to their family and community.

However, it is important, regardless of where it is performed, that conducting treatment is not only marked by access for all patients and that health professionals, especially Nursing, due to their proximity to the patient, act not to contribute to the creation of escape mechanisms by the treated subjects, guaranteeing and adjusting the offer of DOT in the outpatient setting or even sensitizing themselves to the involvement with the differentiated demands of those hospitalized patients.

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