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Abandonment of tuberculosis treatment among patients co-infected with TB/HIV

ABANDONO DO TRATAMENTO DE TUBERCULOSE EM CO-INFECTADOS TB/HIV

ABANDONO DEL TRATAMIENTO DE LA TUBERCULOSIS EN COINFECTADOS TB/HIV

Ivaneide Leal Ataíde Rodrigues¹, Larissa Lima Monteiro², Régia Hevelline Barros Pacheco³, Sílvio Éder Dias da Silva⁴

ABSTRACT

This study aimed at analyzing the reasons that patients co-infected with tuberculosis and HIV leave the treatment of tuberculosis and to know the conduct of the health team toward that abandonment. The study, using a qualitative approach, performed semi-structured interviews on 45 professionals working at a referral health center in Pará state. Two units emerged based on the thematic analysis: patient-associated factors that make TB treatment adherence difficult; and service-associated factors that contribute to treatment abandonment. It was found that, in terms of the patients, that their low socioeconomic condition was the most common factor that led to abandonment. Other factors that led to this outcome included the adverse drug effects, the use of illegal drugs, and poor personal motivation. Regarding the service, issues related to the physical structure, working process organization and accessibility were also relevant to their non-adherence. Results show there is a need to change the practices performed at the health care services.

KEY WORDS

Tuberculosis.
Endemic diseases.
Acquired Immunodeficiency Syndrome.
Treatment refusal.
Patient care team.

RESUMO

Este estudo objetivou analisar os motivos que levam os pacientes coinfectados TB/HIV a abandonar o tratamento da TB e conhecer a conduta da equipe de saúde frente a esse abandono. A abordagem foi qualitativa. Utilizou-se a entrevista semiestruturada, aplicada a quarenta e cinco profissionais que atuam em uma Unidade de Referência no Pará. Após análise temática, foram construídas duas unidades: fatores relacionados aos doentes que dificultam adesão ao tratamento da TB; e fatores relacionados ao serviço que contribuem para o abandono. Mostrou-se, com relação aos pacientes, que a baixa condição socioeconômica foi o fator mais frequente que propicia o abandono. Também efeitos adversos dos medicamentos, uso de drogas lícitas, e pouca motivação pessoal facilitam esse desfecho. Quanto ao Serviço, as questões relacionadas à estrutura física, organização do processo de trabalho e acesso mostraram-se relevantes para não adesão. Os resultados apontam para a necessidade de alterar as práticas desenvolvidas nos Serviços.

DESCRIPTORES

Tuberculose.
Doenças endêmicas.
Síndrome de Imunodeficiência Adquirida.
Recusa do paciente ao tratamento.
Equipe de assistência ao paciente.

RESUMEN

Este estudio objetivó analizar los motivos que llevan a los pacientes coinfectados de TB/VIH a abandonar el tratamiento de la TB y conocer la conducta del equipo de salud frente a dicho abandono. El abordaje fue cualitativo. Se utilizó la entrevista semiestructurada, aplicada a cuarenta y cinco profesionales que actúan en una Unidad de Referencia en Pará. Luego del análisis temático fueron construidas dos unidades: factores relativos a los enfermos que dificultan su adhesión al tratamiento de la TB y factores relativos al servicio que contribuyen al abandono. Se demostró, con respecto a los pacientes, que la baja condición socio-económica fue el factor más frecuente que propicia el abandono. También los efectos adversos de los medicamentos, el uso de drogas lícitas y la poca motivación personal facilitan ese desenlace. Respecto del Servicio, las cuestiones relacionadas a la estructura física, organización del proceso de trabajo y acceso mostraron relevancia para la no adhesión. Los resultados apuntan a la necesidad de alterar las prácticas desarrolladas en los Servicios.

DESCRIPTORES

Tuberculosis.
Enfermedades endémicas.
Síndrome de Inmunodeficiencia Adquirida.
Negativa del paciente al tratamiento.
Grupo de atención al paciente.

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INTRODUCTION

Tuberculosis (TB) is an ancient disease, however, it is still an important public health problem not only in Brazil but worldwide. The increased incidence of TB is related to several causes, including poverty and social inequality; negligence and/or inappropriate diagnosis and treatment of new cases; inadequate information about the disease; demographic variations; the impact of infection due to HIV. Failures in global TB control with largely ineffective programs have contributed to mortality and multi-drug-resistance⁽¹⁾.

Brazil is ranked 18th among countries with the heaviest load of tuberculosis in the world. The percentage of cure in 2007 in the country was 77% with a 6.9% rate of treatment abandonment⁽²⁾. In this same year, 72,800 new cases of the disease were reported with a coefficient of incidence of 38.2/100,000 inhabitants and an occurrence of 4,500 deaths; 70% of cases are concentrated in 315 of the 5,565 Brazilian cities. The highest rates of incidence are in the states of Rio de Janeiro (73.27/100,000), Amazonas (67.60), Pernambuco (47.79), Pará (45.69) and Ceará (42.12). The Midwest region presents the lowest rate in the country: 9.57/100,000 inhabitants in Goiás⁽³⁾. In recent years, a stronger negative impact in TB control has been observed in large cities due to the population's worsened socioeconomic conditions. The data from the Southeast region is more alarming, where the rate of co-infection with the Human Immunodeficiency Virus (HIV) is at its highest⁽⁴⁾.

Abandonment of TB treatment is frequent and has become a severe problem in Brazil, especially when it occurs in patients with TB/HIV co-morbidity. Studies carried out in Brazil show levels of abandonment that vary from 38%⁽⁵⁾ to 42%⁽⁶⁾, which are exceptionally high rates considering that the Ministry of Health recommends only 5% as an acceptable rate of abandonment⁽⁷⁾. Abandonment is considered to be when a patient starts the treatment and then stops visiting the health unit for more than 30 consecutive days after the date scheduled for return⁽⁷⁾. Abandonment is one of the main obstacles and challenges in the fight against the disease and its direct consequences are increased cost of treatment, mortality and relapse rates, in addition to facilitating the development of resistant strains of the bacillus. Generally, the factors associated with abandonment are related to the patient, modality of the employed treatment and health services⁽⁸⁾.

The attitudes of the health team are highly relevant for treatment success, seeking to clarify for patients the nature of their disease, duration of treatment, importance of regular use of medication and severe consequences of interrupting the treatment. Follow-up with a psychologist, supervised dosages of medications and monthly bacterio-

logical exams are actions that favor curing TB, which enables higher survival rates with quality of patients infected with TB/HIV.

In 1998, the Brazilian Minister of Health launched the National Tuberculosis Control Plan (NTCP), which, among other goals, established the implementation of the Directly Observed Treatment Short Course (DOTS), which includes a set of measures defined and recommended by the World Health Organization based on five pillars: political compromise with TB control, availability of diagnosis by smear, regular supply of medication, efficient Information Systems and directly observed treatment. Rates of cure previously below 50% in several countries (e.g. China, Peru, Bangladesh) were raised to between 80% and 95% after this strategy was adopted⁽⁹⁾.

This study addresses the response of the health team in the face of the abandonment of TB treatment by patients co-infected with TB/HIV, since the efforts made by public policies and professionals working in the disease treatment have had, for the most part, little success in changing the scenario of tuberculosis as a public health problem. The health team should be more careful and pay more attention to patients infected with HIV; these patients need to be encouraged to complete the treatment regime in order to attain a cure, to achieve higher rates of survival and avoid infecting other people.

Hence, this study analyzes the perspective of the health team of a center of excellence for the reasons that lead patients co-infected with TB/HIV to abandon TB treatment and also learn how the health team responds to this abandonment.

...the efforts made by public policies and professionals working in the disease treatment [TB/HIV] have had [...] little success in changing the scenario of tuberculosis as a public health problem.

METHOD

This qualitative study⁽¹⁰⁾ was carried out in the Unit Specializing in Infectious and Special Parasitic Diseases (USISD) in Belém, PA, Brazil. This is a center of excellence in the state of Pará, where people with HIV and co-infected with TB/HIV are treated. Its working hours are from Monday to Friday, from 8am to 7pm. It has functioned for 19 years offering multiprofessional care, including physicians, nurses, social workers, psychologists, pharmacists, physiotherapists, occupational therapists, nutritionists and nursing technicians. This center also depends on the service of the Day Hospital, which has the same working hours. Although the NPTC has adopted supervised treatment (DOTS) as a way to increase the probability of patients being cured, the treatment provided for patients co-infected with TB/HIV in the unit is self-administered.

The study project was approved by the Ethics Research Committee at the State University of Pará and by the unit's directors.

Forty-five professionals participated in the study: six social workers, nine nurses, six physicians, four psychologists and 20 nursing technicians who work in the morning and afternoon shifts and care for patients with TB/HIV co-morbidity. The reports were collected through a semi-structured interview with a script containing open questions.

The professionals in the unit were initially contacted and invited to participate in the study and interviews were scheduled with those who consented. Interviews were carried out in the unit according to participants' working hours. A free and informed consent form with information concerning the study's objectives and how it would be developed was presented to all participants. Each participant chose an alias in order to protect their identities and ensure confidentiality, complying with the study's ethical standards. Participants agreed that reports would be recorded for later verbatim transcription.

Information was analyzed using thematic analysis, to better understand the reality of experience through the reports of individuals who are connected to this reality⁽¹⁰⁾.

RESULTS AND DISCUSSION

As a result of the analysis of the reports, two thematic units were constructed and denominated: factors related to patients that hinder adherence to TB treatment, and factors related to the service that contribute to abandonment.

Factors related to patients that hinder adherence to TB treatment

This unit was based on the grouping of some factors related to patients, which according to the participants lead to treatment abandonment. These are either individual factors linked to socioeconomic or cultural conditions or are related to patients, such as: side effects of medication, the use of legal drugs and lack of motivation.

The patients' low socio-economic condition is the most frequent reason leading to the abandonment of TB treatment.

[...] many patients have very poor socioeconomic conditions, sometimes they don't have food and say: how can I take a medication if I don't have money to eat [...] (Lily).

[...] poor socio economic conditions also cause patients to abandon the treatment, they don't have the means to eat, lack of education of the majority make them to abandon it [...] (SESPA physician).

In the view of this study's participants, socioeconomic factors significantly influence TB treatment abandonment since they report that a low level of education and lack of financial resources are important factors that lead to treatment abandonment. These factors are manifested in the perception patients hold of health problems and which interfere in their adherence to therapeutic regimens⁽¹¹⁾.

The side effects of tuberculostatic drugs appear as the second most mentioned factor and which influence interruption of the TB treatment, whether these are minor reactions (nausea, vomiting, diarrhea) or due to the occurrence of drug-induced hepatitis.

[...] the quantity of pills [...] leads to abandonment, the anti-retroviral have a series of side effects, associated with the side effects of tuberculostatic drugs, patients complain a lot of such effects [...] (Ana).

[...] the disorders in the first days of the treatment lead to abandonment, [...] they generally have gastritis problems, vomiting, diarrhea and quit the treatment [...] (Zinha).

The majority of patients undergoing TB treatment manage to complete it within the recommended time period without suffering any side effects, though when this treatment is associated with some anti-retroviral, drug interactions and adverse reactions are worse than those experienced by HIV-negative individuals. The HIV infection predisposes individuals to more adverse effects. Therefore, it is important to consider that appropriate adherence in both schemes is a great challenge for patients when concomitantly implemented due to the high quantity of pills to be taken every day and the occurrence of side effects, particularly in the first weeks of the treatment. For this reason, the anti-retroviral scheme has to be chosen taking into account the risk of intolerance, toxicity and the patient's ability to adhere, even considering the possibility of postponing its commencement in those patients with less severe immunodeficiency⁽¹²⁾.

A third important and frequent factor that promotes abandonment of treatment is the use of legal drugs.

[...] many patients are alcoholic and smokers [...] so they prefer to keep their vice rather than taking the medications [...] (SESPA physician).

This factor can be attributed to the difficulties inherent in chemical dependency, which are detrimental to the responsibility required by the health service to maintain treatment regularity. There is a close relationship between the use of legal or illegal drugs and non-adherence, both in the self-administered treatment and the supervised one⁽¹³⁾.

Controlling the treatment of patients with TB/HIV co-infection is even more complex when compared to those affected only by TB. Patients with HIV do not have a good life expectancy since, despite all technological advancements to understand the disease's mechanism of action, a cure has not been developed yet and therefore abandonment of treatment occurs whether by disbelief in a successful outcome or lack of motivation to finish the scheme due to physical debility.

[...] the abandonment of the treatment is associated with AIDS, because they don't have a good life expectancy, the tendency when you have TB is to languish, to lower resistance and lose hope, it's more difficult to treat a HIV

positive patient than those who have only tuberculosis [...] (C.M).

Factors related to the service that contribute to abandonment

The factors related to the service and mentioned with higher frequency that lead to the abandonment of the treatment were grouped together, which are: little or no information concerning TB treatment is transmitted by professionals to patients; poor organized services for the specific control of TB, given that the priority is the treatment for HIV; physical facilities that do not ensure privacy; absence of teamwork; and difficulty accessing the service.

Lack of information about the disease, its potential side effects, the importance of completing the treatment regimen even when symptoms improve, and information about severe consequences if treatment is interrupted, influences treatment abandonment since patients need to be sensitized about factors that aggravate their condition.

[...] the first cause is lack of information, [...] it's essential, especially about the disease, duration of treatment, and the importance of not quitting [...] (Nurse Naná).

[...]lack of information [...] good orientation, because they (patients) think that when they don't have any more symptoms, they're already cured and stop taking the medications [...] (Little Flower).

It is known that appropriate information provided to patients and family members about the disease and the identification of these with the team accompanying the treatment significantly reduce the chances of abandonment^(6,14). Additionally, the poor organization of the control of TB/HIV cases also contributes to TB treatment abandonment.

[...] we don't have a structured TB program here [...] tuberculosis is treated as an opportunistic disease and the therapy is more like an adjuvant, there is no search for those who don't return, when they come to the HIV appointment, then they are treated for the tuberculosis [...] (C.M).

[...] we don't have a strategy to encourage adherence to the TB treatment yet, they're considering supervised treatment [...] there's no space here in this building (...) supervised treatment would be more feasible [...] (Nurse Naná).

Deficiency in the specific control of TB and absence of supervised treatment are highlighted as factors that contribute to abandonment, however, the unit has a program called Therapeutic Home Care (THC) that includes a multiprofessional team, which aims to deliver integral care and treat patients who are unable to go to the unit. This strategy could be used as a way to minimize the problem of treatment abandonment in the cases of TB/HIV co-infection. The self-administered treatment has a higher probability of abandonment compared to supervised treat-

ment⁽⁸⁾. The latter is an important tool in the fight against TB since it holds that patients cannot be considered to be the only ones responsible for their treatment and allows other actors (family members, community and health professionals) to actively participate in the process, though it should be flexible and respect the choices of patients⁽¹³⁾.

There is a large number of co-infected patients cared for in the unit, however, it does not have the physical facilities to meet this demand, and not enough rooms to ensure the privacy of patients and professionals, who usually have to share the space. Neither is there well-structured and organized teamwork, the lack of which hinders patient adherence to treatment because the continuity of care provided by professionals from different categories is essential for one to attain a cure.

[...] there is lack of physical space, I'm in a consultation and soon another professional appears to consult in the same room. We don't manage to provide care to patients as we should [...] there isn't teamwork, each one works separately [...] is every man for himself, I don't know how the physician's work is going, the psychologist [...] (Nurse Costa).

Apparently there is not a specific strategy to improve adherence of patients to TB treatment because even though there is a group who inform HIV positive patients about opportunistic diseases that can affect them, this group only includes TB and does not establish any special strategy to fight it.

The fact that the unit has to meet a large demand from the rest of the state hinders access for those who live in the capital and especially for those who need to travel from small towns in the interior of the state. This limited access impedes them from attending the monthly consultations and assessments. Coupled with this are difficulties in obtaining the Treatment Away from Home program (TAFH), which is directed at those who live in the interior of the state⁽¹⁴⁾.

[...] the distance is another factor that harms adherence [...] even of those who live here (in the capital) they don't have the means to come [...] think about those who live in the interior and depend on a health department to pay for TAFH [...] (Nurse Naná).

[...] The patient who lives away from the unit that provides the treatment ends up quitting [...] usually they don't have the means to come to Belém to attend the consultations, which makes it difficult to maintain the treatment and its control[...] (SESPA physician).

CONCLUSION

This study permitted analyzing the most frequent reasons that lead co-infected patients to abandon TB treatment from the perspective of the health team of the USISD in Belém, PA, Brazil and to learn how the health team responds to this abandonment.

The patients' poor socioeconomic condition is the most frequent and relevant factor that leads to abandonment, though, the adverse effects of medications and the use of legal drugs greatly influences this outcome. Co-infection also leads to abandonment of TB treatment because of the great difficulty in controlling these cases, whether due to aspects related to the treatment itself or patients' lack of motivation caused by the feeling that death is imminent.

In regard to reasons related to the health service, the issues related to the physical structure available, organization of the work process to control TB and difficult access are relevant in the context of non-adherence to treatment.

There is not a specific and efficient conduct performed by the professionals to *rescue* the patients who miss their

consultations or a strategy to seek out those who abandon treatment.

This study's results indicate the need to change the practices developed in the services because they are related to political will whether of health managers or of the professionals themselves and frequently depend on simple attitudes such as: strengthening already existent strategies, encouraging adherence to new strategies as is the case of supervised treatment, and seeking more therapeutic possibilities to reduce the unpleasant effects worsened by the interaction of anti-retroviral and tuberculostatic drugs. However, factors related to patients are more difficult to change since they are related to individual vulnerabilities or are social and economic factors that depend on government actions, which are much more complex to change.

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