

## PERCEPTIONS OF NURSES AND PATIENTS ON ADHERENCE TO THE DIRECTLY OBSERVED TREATMENT IN TUBERCULOSIS

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### ABSTRACT

**Objective:** to analyze the intervening factors in adherence to the directly observed treatment in tuberculosis, in the perception of patients and nurses of basic health units.

**Method:** a descriptive and qualitative research study with the participation of 13 nurses and 52 patients of 12 Basic Health Units of Belém-Pará, Brazil. For data production, individual interviews were conducted, complemented by non-participant observation. The data were submitted to thematic content analysis.

**Results:** two categories emerged from the analysis: Perceptions of patients and nurses on the directly observed treatment, and Operationalization of the directly observed treatment: positive and limiting factors.

**Conclusion:** even with the weaknesses pointed out, the units have potential to develop the strategy. The nurses are aware of their importance, but need greater institutional support, and the patients, when well informed, show good adherence. This knowledge can provide greater safety for the nurses in the conduction of patient follow-up.

**DESCRIPTORS:** Tuberculosis; Directly Observed Therapy; Adherence to Medication; Patient Cooperation; Nursing.

### **PERCEPCIONES DE ENFERMEROS Y PACIENTES SOBRE LA ADHESIÓN AL TRATAMIENTO DIRETAMENTE OBSERVADO EN TUBERCULOSIS**

#### **RESUMEN:**

**Objetivo:** analizar los factores intervinientes en la adhesión al tratamiento directamente observado en tuberculosis, según la percepción de pacientes y enfermeros de unidades básicas de salud. **Método:** investigación cualitativa y descriptiva con la participación de 13 enfermeros y 52 pacientes de 12 Unidades Básicas de Salud de Belém-Pará, Brasil. Para la producción de los datos, se realizaron entrevistas individuales, complementadas con observación no participativa. Los datos se sometieron a análisis de contenido temático. **Resultados:** surgieron dos categorías del análisis: Percepciones de pacientes y enfermeros sobre el tratamiento directamente observado, y Operacionalización del tratamiento directamente observado: aspectos positivos y limitantes. **Conclusión:** incluso con las debilidades señaladas, las unidades tienen potencial para desarrollar la estrategia. Los enfermeros reconocen su importancia, pero necesitan más apoyo institucional; y los pacientes, cuando están bien informados, logran buenos índices de adhesión al tratamiento. Este conocimiento puede proporcionar mayor seguridad a los enfermeros al realizar el seguimiento de los pacientes.

**DESCRIPTORES:** Tuberculosis; Terapia Directamente Observada; Adhesión a la Medicación; Cooperación del Paciente; Enfermería.

## INTRODUCTION

Tuberculosis (TB) is still a major public health problem both worldwide and in Brazil<sup>(1)</sup>, although its treatment is highly effective and is fully available by the Unified Health System (Sistema Único de Saúde, SUS).

Brazil has made efforts to implement TB control. Even so, this country is among the 30 with the highest burden of disease in the world, with an incidence rate of 34.8/100,000 inhabitants in 2018. Pará is the leading state in TB burden in the North region, and Belém has the fifth highest incidence among Brazilian capital cities, with a rate of 62.7/100,000 inhabitants<sup>(2-3)</sup>.

In 2017, only 36.9% of the new cases of pulmonary TB were on Directly Observed Treatment (DOT) in Brazil<sup>(4)</sup>. Belém implemented the DOT strategy in 2001, for 6.7% of the cases. This percentage increased after 2008 with the support provided by the partnership between the Brazilian Global Fund Project and the Ministry of Health, but in 2014 only 44% of the cases were on DOT<sup>(5)</sup>.

In this context, the implementation of DOT in primary health care is a priority to improve cure rates, reduce treatment abandonment, and prevent the emergence of new TB cases. This strategy consists of observing the patients taking the medications daily, or at least three times a week<sup>(6)</sup>.

According to data from the state of Pará<sup>(5)</sup>, it is observed that many municipalities failed to successfully implement this strategy, either due to managerial issues or to those inherent to the people involved in the process, implying rates of cure and treatment abandonment similar to those obtained in a self-administered DOT regime.

Because of this, it was decided to investigate the issues that pervade DOT, based on patients' adherence. It is expected to demonstrate the intervention points for improvement of the DOT operationalization and to contribute to raise nurses' awareness on TB, leading to reduced incidence of disease and benefiting the community. Therefore, this study aimed to analyze the factors intervening in adherence to the DOT in TB and in the perception of patients and nurses in basic health units.

## METHOD

A descriptive and qualitative study conducted in 12 traditional health units (52% of the total) in Belém-PA, which performed DOT at least three times a week, in the selection period of the services, the minimum frequency accepted by the Ministry of Health<sup>(6)</sup>.

The participants were 13 nurses (100% of those performing DOT) and 52 TB patients (50% of those under DOT). In the group of patients, data production was closed using the saturation criterion and when the study objective had been met<sup>(7)</sup>.

The study included patients over 18 years who were on treatment for at least 30 days (time required for adapting to the DOT), users of the units under study, or coming from other health services in Belém. Twenty-one patients were excluded because they came from other municipalities, in order to avoid comparative bias, or had some communication barrier. With regard to nurses, the study included those who worked with DOT for at least one month, due the requirement of some experience with this strategy, and excluded those who were on vacations or leave of absence.

Data was collected from January to June 2016 by individual interviews with a semi-structured script and open questions on the understanding on the DOT, work process, experiences with the strategy, interpersonal relationship, and access to the health services, among others.

The interviews were conducted by the researcher, at a private room in the health unit itself, had a mean duration of 20 minutes, and were recorded on digital media upon consent. The participants were not asked to check the interviews, in order for the speeches not to lose their spontaneity. There was non-participant observation of the work process, material resources, physical facilities, and interaction among the participants at the medication room and the medical office, with an approximate workload of four hours/day, recorded on a field journal.

The invitation to participate and the scheduling of the interviews with the nurses were made during a previous visit at the unit. The patients were approached during the observation, and the interviews were scheduled according to their attendance at the service.

Data was submitted to thematic content analysis<sup>(8)</sup>. The corpus consisted of 100% of the interviews, which were transcribed exclusively by the researcher, double checked with audio recordings, and then reviewed by the study advisor, in order to ensure data reliability. Subsequently, the interviews were read and there was the identification of similar aspects both with regard to answers from the same respondent (vertical analysis) and to the set of respondents' answers for the same question (horizontal analysis), for health professionals and patients.

In the exploration of the material phase, themes were identified, their correlation stratified by occurrence, and co-occurrence was assessed, and the themes were aggregated into registration units (RUs). For the treatment, inference, and interpretation of the results, the RUs were grouped according to the identified themes and organized into two categories: Perceptions of patients and nurses on the DOT; Operationalization of the DOT: Positive and limiting factors. The variables that made up the participants' profiles were tabulated and presented with absolute and percentage values.

The project was authorized by the Municipal Health Secretariat of Belém and approved by the Research Ethics Committee of the State University of Pará, under opinion No. 1,479,099. The possibility of breaching anonymity of the participants' identities was minimized using the following alphanumeric codes: E for the nurses ("*Enfermeiros*" in Portuguese); and CN for new case ("*Caso Novo*" in Portuguese), RR for retreatment and RA for return after abandonment in the case of the patients, followed by the numerical sequence in which the interviews were conducted.

## RESULTS

Of the 52 patients, 34 (65.4%) were male; 38 (73.0%) belonged to the 18-47-year-old age group, and 45 (86.5%) were in the second phase of their treatment. In relation to the nurses, 11 (84.6%) were female, four (31%) were between 42 and 48 years old, seven (54%) had graduated more than 23 years ago, working in the unit from three months to 12 years, and eight (62%) working with DOT between one and eight years.

Of the study units, six (50%) had been performing DOT for between five and eight years, and the other units for a variable period. Of these, four (58.3%) were medium-sized, three (25%) were small, and two (16.7%) were large.

The two categories organized from the results are presented below.

## Perceptions of patients and nurses on the DOT

This category encompassed the perceptions of nurses and patients on the strategy. The two groups understand it as measure to exert control over the patients.

With regard to the patients, 37 (71.1%) described their conception on the DOT, but 20 (38.4%) reported that there was no enough information to provide clear answers:

*How can I tell you... I have to take three pills. Then I have to come here every day to take them (CN 48).*

*I understand that this is a way to monitor people who come to take the medication, because otherwise, some people are given the medication and forget to take it or do not take it because they do not want to. (CN 22).*

It was also sought to know what could improve in the DOT provided. With regard to this aspect, 31 (59.6%) of the patients answered that there was no need for this supervision and that, if maintained, it should occur less frequently:

*I believe the number of days should be reduced, at least every 15 days, because it depends much on the patient knowing that it is necessary to take the medication (CN 24).*

*I think it is just reducing these three days per week to around twice a week. (CN 26).*

For 11 (84.6%) nurses, the DOT is a strategy that guarantees treatment monitoring. This perception is similar to that reported by the patients when they mention "treatment control":

*DOT is monitoring so that you can be sure that the patient is committed to take the medication on a regular basis. (E 3).*

*It is ensuring that the user is taking the medication. So, with the supervised treatment, at least we know that the doses given at the unit have been effectively taken. (E 4).*

## Operationalization of the DOT: Positive and limiting factors

This section aimed to explore the positive and limiting factors of the DOT and their importance to participants. As positive factors, 33 (63.4%) patients reported that this strategy made them receive regular treatment and gain more attention from the professionals:

*The good part is better control for people actually taking medications, because if they didn't come or forget it's because they are not continuing treatment. (CN 30).*

*I think it's good because they are really willing to take care of us, to check if we are taking the dose at the right time. (CN 42).*

Other positive aspects were related to the importance of the DOT and the relationship between patients and nurses. For 47 (90.3%) patients, it is important to attain the cure, and the relationship with the nurses was assessed as good by 48 (92.3%) of them.

*The nurses always say to us to go until the end. Because, when we start to take the medication, we start to feel better and think that it's enough. We have to follow the full six months of treatment (CN 34).*

*I like (the nurse) a lot. She's a very good person. She treats people well. She cares for the people who are there, she treats them very well. (CN 43).*

With regard to the nurses, eight (61.5%) considered the possibility of monitoring the patients' evolution as positive:

*I consider it important, because they're often provided with the medications but don't taken them properly. (E 3).*

*It is good that I'm certain of what I see. (E 5).*

For 12 (92.3%), watching the patients take the medications is positive, even if with difficulties in monitoring them:

*My experience is satisfactory, but I would like it to be excellent. However, due to some obstacles related to the patient, the institution, and other things, it is not how I'd like it to be. (E 1).*

*As a professional, it is important because we see the effectiveness of the treatment.. Now, as a person, I understand the patient side when they find it bad to come to the unit. (E 2)*

In relation to the limiting aspects, 47 (90.3%) patients mentioned not having been consulted on the possibility of performing the DOT, merely following the guidelines received, understood as an imposition:

*Coming on Monday, Wednesday and Friday was not easy. But, since I've recovered and have to move on with life, I decided to adhere to the treatment. (CN 4).*

*I've been referred from the private network and here they told me how I should follow the treatment. In this unit, it is routinely administered three times per week. (CN 46).*

Another limiting factor for 34 (65.3%) of them was having to go to the unit many times a week, which resulted in work absences for 14 (41%) and in higher transportation costs for eight (23.5%):

*Because I came here every day, I've been fired because they found that I was ill [...]. I am waiting to end the treatment so as to see if I get some job. (CN 20).*

*For me it's hard, because I live far from here, I work, and I have to take the bus. Paying R\$ 5.00 every time is bad. It's R\$ 150.00 per month. (CN 50)*

The fact of never being seen by other professionals was negatively reported by 28 (53.8%) patients, who stated that these occurred only in case of need:

*I requested to see the diabetes doctor and I waited for hours. They asked me to wait in a room and, the time for the consultation came, they asked me to go to another room. When we got to the other room, there was a very long line already. Then I got upset! (CN 13)*

*My relationship with the team working at the DOT room is good, but I don't have much contact with the other teams of the unit. I only have contact with the doctor when I arrange an appointment [...] (CN 35).*

As a limiting factor, nine (69.2%) nurses reported lack of incentives (breakfast, transportation allowance, or basic food baskets) for the patients. Four (30.7%) understand that these strategies could improve adherence:

*They are poor patients and we have little to offer [...]. It's very complicated for the patients to come by bus, they sometimes don't have the money. There were some patients who abandon treatment because we stopped offering breakfast. (E 10).*

*Transportation allowance would be very important, because my area is very large and the patients have many difficulties coming here. They live in poor conditions, they have no money. Some patients here have barely something to eat. (E 7).*

Another limiting factor reported by nine (68%) nurses was lack of partnership with other health professionals. Despite the good relationship between them, there was little multi-professional collaboration in the care of patients with TB:

*People are still afraid of TB [...]. That's the real truth. Not all health professionals like to work with communicable diseases, due to fear of contagion. (E 1).*

*The DOT works only in the morning. The team is a nursing technician, a doctor, and me. Other professionals seldom follow-up the patients. (E 14).*

During the observation, difficulties related to the physical structure were verified. Biosafety administrative measures were applied in only three (25%) units. In the others, inadequate waiting rooms were shared with other patients. In at least four (33.3%) units, there was only one Nursing office for the entire demand.

With regard to environmental control, six (50%) waiting rooms had air conditioning. Only two (33.3%) were exclusive for communicable diseases. In the rooms with windows, these were poorly located, and the fans were incorrectly positioned. The nurses did not take any individual protective measures for treating any patient.

## DISCUSSION

In the perceptions on the DOT, it was identified that, for the patients, elements to understand this strategy better were lacking, since it was explained as a synonym for attending the unit to take medications. This difficulty shows the disconformity between the guidance provided and what is actually assimilated by the patients<sup>(9)</sup>. For the nurses, in turn, this control made them feel confident that they were providing the appropriate treatment.

Accurate information equips patients to make a conscious choice supporting the required agreements. In the Nursing Protocol of the DOT<sup>(10)</sup>, one of the goals is guidance for the promotion of adherence. It was observed that few professionals value the educational activity, or performed it in an impersonal manner, which could reinforce a vertical and sometimes authoritarian relationship<sup>(11)</sup>. This increased communication difficulty can have an influence on the imaginary of the subjects involved, turning the professionals into holders of knowledge and the patients into people unable to understand information<sup>(12)</sup>.

A study conducted in São Paulo showed that the DOT presents significant cure rates, reduced rates of abandonment, and reduced occurrence of new cases<sup>(13)</sup>. However, there were frequent patients' absences, and search strategies were limited to phone calls or occasional home visits.

Worldwide, several attempts have been made to attract and maintain patients on DOT. In 2011, Ecuador implemented a monetary incentive program for patients in treatment for drug-resistant TB. This strategy reduced absenteeism and abandonment<sup>(14)</sup>. In Brazil, the experiences vary according to the availability of resources and to the extent of managerial commitment. Strategies for food and transportation allowance were more common than giving money in cash<sup>(15)</sup>.

In 2015, nearly 45% of the municipalities with priority for TB in Brazil offered some type of benefit to the patients, but these benefits did not cover 100% of the cases under treatment and were not provided on a regular basis<sup>(15)</sup>. Currently, no health unit in Belém receives these benefits. Some nurses use creativity to engage the patients.

With regard to the operationalization of the DOT, the Nursing team was the most mentioned by the patients. The nurses were available for the strategy for a considerable time, even though not exclusively, and their offices were freely accessible. This fact favored the approximation between nurses and patients and was acknowledged as a treatment facilitator, because the bond promotes adherence as a result of positive attitudes between nurses and patients<sup>(16)</sup>.

Despite acknowledging the experience of the DOT as positive, the nurses pointed out negative conditions and expressed solidarity to the patients who faced them, assessing socioeconomic status, social vulnerability, and risk for abandonment, among others, aiming to reduce the frequency of attendances to the unit without putting treatment continuity at risk. Thus, most of the patients attended the service three times a week.

With regard to limiting factors, the fact that the patients were not consulted on DOT adherence made them mention expressions such as imposition, rule, order, and routine. The choice of the treatment modality was always agreed upon between the health team and the patients, considering the local reality and the service structure<sup>(6)</sup>.

The low multidisciplinary participation contributed for the little interaction with the patients because, when welcoming is conducted by a multi-professional team, both communication with the patients and the relationships among the professionals themselves are favored, thus improving the performance of the entire group<sup>(17)</sup>.

According to the nurses, the patients met when breakfast was offered. A study conducted with patients under treatment for TB, medical students and physicians showed the importance of this interaction for the strengthening of treatment adherence and the need for dialog in health care<sup>(18)</sup>.

The relationship between frequency of attendance to the unit and patients' professional activity was important. Some patients reported not mentioning that they were on treatment for TB due to fear of retaliation, and there were reports of patients who lost their job. Social stigma is likely to produce negative reactions, and fear of discrimination leads patients and their families to avoid speaking about the disease with their community and work acquaintances<sup>(19)</sup>.

Since the Family Health Strategy (FHS) coverage is beyond that required in the municipality, many patients need to seek care in traditional health units, bearing transportation costs and changing their routines. Some patients need to take their children with them, which increases expenses and exposes the children to several risks. An integrative review on abandonment of TB treatment showed that one of the factors associated with treatment interruption is living far away from the health service and not having time for traveling<sup>(20)</sup>, reflecting the need to improve geographical access.

When asked about "incentive", the patients reported the encouragement given by the nurses. Although these answers were mistaken with regard to what the question wanted to assess, they ended up showing the support they received. These findings are in line with an analysis on the influence of incentives to patients with TB in São Paulo, which concluded that incentives strengthen adherence, but the bond with professionals helps to know the patients' needs and to value, welcome, and promote social inclusion<sup>(21)</sup>.

A study on mortality due to TB showed how social inequalities affect the increase in the number of deaths. The reduction in this number must consider factors such as access to the health services, coordination of control actions and surveillance<sup>(22)</sup>, requiring governmental strategies for the confrontation of deeper issues that have a direct impact on people's health.

The nurses' judgment on the good relationship with other health professionals was based on interpersonal contact, since there was a remarkable difficulty in collaboration in the work relationships, which is a consequence of several factors: scarce human resources, fear, and difficulty of interaction, among others. The acknowledgment of negative social representations made by nurses with regard to people with TB, based on fear, tends to weaken the relationship between nurses and patients, reinforcing prejudice and exclusion<sup>(23)</sup>.

In 100% of the services, nurses participated directly, but not exclusively, in the DOT, which compromises patient care and shows the need to increase the Nursing workforce. Excessive workload and bureaucracy in the health services often collaborate to reducing

qualification of care, and prioritization of standards and regulations frequently overlap care<sup>(24)</sup>. This scenario is compatible with the reality observed in this study and helps demonstrate the need to improve the working conditions and health management in its different levels of responsibility.

It is understood that this study has limitations, since it does not consider other variables that could broaden the discussion, such as sharing the DOT with referral services; however, it can contribute to elucidate factors that favor or hinder adherence to the DOT in Belém, leading to the reflection that health professionals need to bear in mind the values and needs that can have an influence on commitment to the treatment to define the therapeutic plan to be used. It can also encourage other research studies on the theme in similar realities.

## CONCLUSION

It was concluded that the intervening factors in patients' adherence to the DOT are mainly related to low knowledge on this strategy and to the unfavorable socioeconomic situation in which most patients live. It was also possible to observe that the nurses' working conditions hinder actions, sometimes compromising quality of care.

Although the patients reported some positive factors for their adherence, low understanding has an influence on comprehending its importance and emerges as a weakness. Even though, empathy between nurses and patients allows them to overcome good part of the challenges. Unfortunately, this posture is not shared by other health professionals and reflects on the access of people with TB to other individual and collective demands.

Due to the need to obtain the cure, nurses end up imposing the DOT on the patients, although empathizing with the patients' difficulties and advocating for the presence of material incentives for them. This is a risky practice, because it is not able to overcome the barriers imposed on their routines and increases the possibility of treatment abandonment.

It is considered that, in the municipality of Belém, the DOT offers conditions to attain good results. However, there is the need to invest in the structuring of the health services and on establishing partnerships to ensure rights and support.

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