

# Tuberculosis: supervised treatment in North, West and East Health Departments of São Paulo

TUBERCULOSE: TRATAMENTO SUPERVISIONADO NAS COORDENADORIAS DE SAÚDE NORTE, OESTE E LESTE DO MUNICÍPIO DE SÃO PAULO

TUBERCULOSIS: TRATAMIENTO SUPERVISIONADO EN LAS COORDINACIONES NORTE, OESTE Y ESTE DE LA MUNICIPALIDAD DE SÃO PAULO

Elisangela Martins de Queiroz<sup>1</sup>, Maria Rita Bertolozzi<sup>2</sup>

## ABSTRACT

This study had as objective to analyze the strengths and weaknesses of the Directly Supervised Treatment strategy (DOTS) from the view of patients and workers from the North, West and East Health Departments of São Paulo. The analysis of the statements was based on the Social Determination Theory of the Health-Disease process. In general, the DOTS makes it possible to establish attachments and that treatment adherence is associated with the need of returning to work. The identified weaknesses were the health professionals' lack of involvement in the treatment and the irregular distribution of incentives. Results show that treatment adherence transcends the biological and individual scope, and that it is central that health professionals recognize patients as people who have specific needs that are not limited to the tuberculosis treatment.

## KEY WORDS

Tuberculosis.  
Directly observed therapy.  
Treatment refusal.  
Patient care team.

## RESUMO

O estudo objetivou analisar potencialidades e limites da estratégia do Tratamento Diretamente Supervisionado (DOTS), sob o ponto de vista de pacientes e trabalhadores de Unidades Básicas de Saúde das Coordenadorias Norte, Oeste e Leste, do Município de São Paulo. Os depoimentos foram coletados, após consentimento livre e esclarecido, e decodificados por meio de técnica de análise de discurso. Tomando-se como referencial teórico a Teoria da Determinação Social do Processo Saúde-Doença, de modo geral, identificou-se que o DOTS possibilita a criação de vínculo e que a adesão ao tratamento se associa à necessidade de volta ao trabalho. Os limites identificados foram: o não envolvimento dos profissionais no tratamento e a irregular distribuição de incentivos. Os achados revelam que a adesão ao tratamento transcende o âmbito biológico e individual, apontando-se como fundamental que os trabalhadores de saúde reconheçam os pacientes como portadores de necessidades, que não se restringem ao tratamento da tuberculose.

## DESCRIPTORES

Tuberculose.  
Terapia diretamente observada.  
Recusa do paciente ao tratamento.  
Equipe de assistência ao paciente.

## RESUMEN

El estudio objetivó analizar las potencialidades y límites de la estrategia del Tratamiento Directamente Supervisado (DOTS), de acuerdo el punto de vista de pacientes y empleados de Unidades Básicas de Salud de las Coordinaciones Norte, Oeste y Este de la Municipalidad de São Paulo. Las entrevistas fueron recolectadas con consentimiento libre y aclarado, y decodificadas a través de la técnica de análisis del discurso. Se tomó como referencia teórica la Teoría de la Determinación Social del Proceso Salud-Enfermedad. De un modo general, se identificó que el DOTS posibilita la creación de vínculo y que la adhesión al tratamiento se asocia a la necesidad de volver al trabajo. Los límites detectados fueron la ausencia de compromiso por parte de los profesionales respecto del tratamiento y la distribución irregular de incentivos. Los hallazgos revelan que la adhesión al tratamiento trasciende los ámbitos biológico e individual, apuntándose como fundamental el hecho de que los trabajadores de la salud reconozcan a los pacientes como portadores de necesidades que no se restringen al tratamiento de la tuberculosis.

## DESCRIPTORES

Tuberculosis.  
Terapia por observación directa.  
Negativa del paciente al tratamiento.  
Grupo de atención al paciente.

<sup>1</sup> RN, University of São Paulo, College of Nursing. São Paulo, SP, Brazil. elismq@yahoo.com.br <sup>2</sup> RN, Associated Professor, University of São Paulo, Department of Nursing in Collective Health. São Paulo, SP, Brasil.mrbertol@usp.br

## INTRODUCTION

This study integrates the line of research concerning the analytical category *adherence*. It refers to a set of studies<sup>(1-3)</sup> indicating that adherence to tuberculosis treatment goes beyond the approach that reduces health problems to clinical and biological aspects and which in general considers multiple factors for the health-disease continuum under the form of variables or attributes of the human being, restricting health interventions to such a dimension.

The epidemiological importance of tuberculosis is unquestionable. According to the World Health Organization (WHO), in 2007 there were 13.7 million people carrying the disease, of which about 9.2 million were new cases; TB has victimized 1.3 million people. Brazil occupies the 14<sup>th</sup> position in the ranking of 22 countries concentrating 80% of cases in the world with about 114,000 patients, which correspond to a prevalence of 60/100,000 inhabitants<sup>(4)</sup>.

In 1993, the WHO established a state of emergency and advised countries to adopt strategies to improve disease control, such as the implementation of the Directly Observed Treatment Short course (DOTS) with a view to achieve the goals established in relation to treatment success (85%) and case detection (70%), and to lessen treatment abandonment<sup>(5)</sup>.

The state of São Paulo, in Brazil, adopted the strategy in 1998 and in 2004 its coverage grew in 68.89% of the priority cities<sup>(5)</sup>. The DOTS coverage in 2004 in the city of São Paulo was 29.3% (20.9% in the Midwest, 22.9% in the Southeast, 33.2% in the East, 48.8% North and 56% in the South regions), a rate of incidence of 61/100,000 inhabitants, higher than the national average (48.4 in 2000), and also a rate of abandonment of 6.9%, higher than that recommended by WHO<sup>(6)</sup>. This situation reflects conditions that concretize the disease as directly associated with social exclusion in its most diverse forms of expression, resulting from marginalization, unemployment, unhealthy housing, migration and the growth of AIDS, among others. A more recent challenge is the multi-resistance to drugs as a consequence not only of treatment abandonment but also inappropriate therapeutic regimens. All these issues compose a mosaic in which tuberculosis is presented as a problem to be overcome by health professionals.

Hence, this study seeks to deepen the understanding of DOTS implementation in the city of São Paulo by the Coordinating Health Units in the North, East and West regions, determining strengths and difficulties of the implementation process.

## OBJECTIVE

Considering the potential of Supervised Treatment (ST) to achieve the WHO goals, especially those concerning the

reduction of treatment abandonment, this study determines treatment strengths and difficulties according to the perception of workers in the tuberculosis control in Basic Health Units and of patients submitted to the treatment and yet, propose alternatives to improve its implementation.

## METHOD

Patients and health workers participated in this qualitative study. The sample was not defined *a priori*, because the depth and diversity of reports, more than quantity, would be taken into consideration. Interviews were carried out with 11 patients and 12 health professionals working in nine Basic Health Units (BHU). Since the objective was to identify the implementation of DOTS in the city of São Paulo and the Central, Sapopemba, Butantã and South regions had already been investigated<sup>(3)</sup>, the regions that had not yet been object of study were chosen for this study: North, East and West.

The Project was submitted to and approved by the Research Ethics Committee of the Health Department of the city of São Paulo (protocol 092/05). Data were collected through two pretested semi-structured scripts: one for patients and the other for health workers. Interviews were recorded and transcribed verbatim. The individuals were invited to participate in the study after being informed through a written consent form. All patients undergoing treatment were identified with the help of workers from the BHUs and invited to participate in the study. The workers' inclusion criterion was being responsible for supervising or coordinating DOTS in the BHU and the criterion for users was undergoing DOTS. Data collection was carried out between April and June 2006 on the BHUs' premises, preserving the participants' privacy.

Empirical material was analyzed through Meaning-Text Theory, which permits the understanding of thematic phrases<sup>(7)</sup>. This process revealed the themes that compose the participants' perceptions concerning the main question: the treatment under DOTS strategy and how treatment adherence is established, what are the strengths and difficulties involved in treatment continuity (or discontinuity).

The discussion was based on the Social Determination Theory of Health-Disease. Hence, the interpretation of the perceptions of health workers and patients undergoing DOTS is based on the historical view of the health-disease process. From this perspective, human life is conceived as non-static and is characterized by continuous transformation. The perceptions of the participants depend on the place they occupy in society and how they live. The biological processes are part of the whole of social life. Therefore, health and disease are taken to be part of a larger whole, which is life<sup>(8)</sup>.

...reflects conditions that concretize the disease [tuberculosis] as directly associated with social exclusion...

## RESULTS

### *The participants*

Of the total patients, three were women and eight were men. The average age for both genders was 44 years old: 39.5 years old for men and 56 years old for women. The majority were from other states, especially the Northeast, but had lived in São Paulo for more than 15 years. All patients had pulmonary tuberculosis; four were in the second month of treatment, three in the third, two in the fourth month and another two in the fifth month of treatment.

In regard to the participants' occupations, two were on sick-leave, three were self-employed (bricklayer, care-taker, carpet installer, three were pensioners, one was a messenger and one was a government employee (in maintenance). Five patients reported asking for financial help from family members.

The majority lived with their families (wife, husband, parents, children, siblings, grandchildren) and the average number of people by household was 3.7. One patient lived in an apartment, two in wooden houses, seven in masonry houses and one lived alone in the country house where he worked. The patients' average years of education was 5.3 years and one of them was illiterate. The schooling levels of the mothers of four participants were unknown, four mentioned that their mothers had not studied, one had two years of education, another five years and a third had four years of education.

Twelve health workers were interviewed: five nurses, four nursing auxiliaries, two community agents and one physician. The majority were female (10); the average age was 43.8 years old; they worked in the profession for an average of 12.4 years and in the health unit for an average of 6.8 years, and specifically in the tuberculosis field for 1.7 years.

### *Patients' perceptions*

#### 1. About Health and Disease

1.1 Knowing you have tuberculosis is horrible and threatening; it generates feelings of guilt and changes in daily habits.

1.2 Tuberculosis (TB) is an *insidious* disease that *kills silently*.

1.3 TB is bad for its signs and symptoms, side effects and large number of medications.

1.4 The disease leads to isolation; even from family members.

1.5 Tuberculosis can be mistaken for AIDS due to sudden weight loss.

1.6 Poor knowledge about TB before becoming sick and non-association with signs and symptoms.

1.6 The disease reorders life

#### 2. About Supervised Treatment (ST)

2.1 The strategy is defended based on the following: smaller chance to forget or stop taking medication due to clinical improvement; opportunity to leave the house and walk since DOTS is carried out in the BHU.

2.2 Feeling safe and well cared for ("supported") by professionals overseeing the treatment both during the observation of taking medication and monthly medical visits.

2.3 Only one patient reported feeling "obliged" to follow the ST.

2.4 The staple foods basket provided by the health unit are not delivered with the regularity guaranteed by the health unit.

2.5 Patients need the benefits due to their poor living conditions.

#### 3. About Treatment Adherence

3.1 Appropriately following ST alleviates symptoms and enables patients to resume their daily activities, especially work.

3.2 It is effected due to one's *desire to live*, to be with the family in addition to faith in God.

3.3 Adherence is related to family support (mainly) and to the support provided by the health unit.

3.4 The following hinder adherence: difficulty in reconciling work hours (which provides their living) with the health unit and also the large number of medications.

### *Health Professionals' Perceptions*

#### 1. About the Health-Disease Process

1.1 Patients feel discriminated against, stigmatized, *rejected*, powerless, sad, fearful of dying and contaminating family members; they suffer from people's prejudice including family members' and due to poor knowledge concerning the disease and its consequences (especially in relation to their chances of going back to work).

1.2 Patients *exclude themselves* from social life for fear of harming others. Hence, they look for treatment far away from their house.

1.3 TB symptoms are considered *progressive and debilitating* and responsible for the shame the patient experiences in the face of others.

#### 2. About Supervised Treatment

2.1 ST is *difficult* and *tiresome* for patients because they have to go to the health unit daily, which in general implies in stopping working.

2.2 Patients like ST because they *feel they have attention*.

2.3 ST onset is considered the most difficult phase, marked by patients' lack of trust in supervision.

2.4 Behavior that facilitates supervision: make the patient not to feel she/he is being observed, *play*, bonding so that taking medication occurs in a friendly environment (*they feel at home*), provide an environment in which patients feel safe, talk about the treatment's positive aspects, convince the patient that observing is a function of professionals, and highlight the benefit of benefits such as the staple food basket.

2.5 Positive aspects of ST include: cure; certainty of taking medication; the possibility of having a daily moment to reinforce the need for the treatment; the good relationship between professional and patient; ties; proximity of professionals, which enables them to know about the patients' histories, development of their condition, share with them the cure and encourage them; and flexibility of hours.

2.6 Negative aspects of ST include: patients have to go to the BHU daily, to the detriment of their work, family pressure, and poor professional-patient relationship. Non-committed, non-engaged professionals, who do not realize the importance of a good relationship, making the treatment difficult for the patient as interaction is not friendly.

2.7 The irregular distribution of the staple food basket (incentive considered to be the most important given the patients' poor living conditions) hinders ST as it weakens the relationship of trust between patients and professionals.

2.8 One Professional reported omitting information about medication side effects, aiming to reassure patients.

2.9 Given the strategy limitations, the following have been considered: possibility of ST to be carried out in the patients' households; adopting a different scheme with smaller duration and number of medications; need to *sensitize* professionals in order to address the importance of welcoming patients and bonding; increase the number of human resources so that professionals are able to spend more time with patients instead of in bureaucratic services.

2.10 The Family Health Program (FHP) is conceived as a strategy that enables bonding with patients and detection of new cases of tuberculosis.

### 3. About Treatment Adherence

3.1 Adherence is related to: the patient (having knowledge about the disease, *self-love*, *responsibility for life and self-care*, being *aware*, being concerned with the family and with work, desire to get well, to be cured and not to die); support from family and the health team; bonding with a professional in whom the patient trusts and with whom he/she feels comfortable.

3.2 Unemployed people and individuals who are at a low socioeconomic level are those who most adhere to treatment. Those who believe they are healed after symptoms improve, alcoholics, addicts, smokers, HIV carriers, homeless, those who believe they will die due to the disease and those who never underwent long periods of treatment do not adhere to treatment.

3.3 The following facilitates adherence: the health team contacts the patient's place of work; flexible hours of taking medication according to the patients' daily needs; better access to the health service in relation to exams and availability of medication and; being cared for by professionals who like to work with TB and do not have a prejudice regarding it, and by a *good nursing team*.

## DISCUSSION

Reports reveal that learning about tuberculosis generates emotional impact due to the negative representations of the disease, which have persevered for centuries. The results found in this study are in agreement with that of others concerning the fact that there are patients who do not even mention the word Tuberculosis (*thing*) and do not accept the diagnosis. It reflects the perseverance of stigma and discrimination<sup>(9-12)</sup>.

The isolation of patients from others (such as family members) and the segregated use of objects, which worsens discrimination, is a negative practice still recommended by professionals<sup>(12)</sup>. A professional in this study reported acting this way trying to reassure patients. Hence, it is important to emphasize that educational actions should include patients and professionals. These actions should aim for the

autonomy of patients, of groups, collectivity, reinforce their condition as social subjects, capable of self-care and demand that institutions meet their needs<sup>(11,13)</sup>.

In addition to the emotional impact, the physical impact is particularly intense and also leads patients to the perception that the disease is bad. The debilitating symptoms include disability and powerlessness, especially in regard to the labor market since the patient is perceived as unproductive. Patients are unable to sell their labor, which in a capitalistic society means loss of legitimacy and personal dignity<sup>(2-3,11)</sup>.

Non-association of symptoms with tuberculosis was verified in this study and in another<sup>(3)</sup>, in which, according to the author, the non-association of symptoms represents a difficulty that retards the search for care and arises from a low educational level, which is characteristic of the population in this study, in addition to difficulty accessing information.

In addition to lack of information about the disease, the patients assume the responsibility for having tuberculosis as if the disease were the materialization of punishment for their behavior, which would be outside of the society's standards. Therefore, we verify the expression of self-discrimination<sup>(9,11)</sup>.

This feeling, experienced and feared by patients, is reported in several studies addressing tuberculosis. Patients exclude themselves and feel excluded even by family members and as a consequence, changes in their daily routines are also noted<sup>(9,10)</sup>.

A situation in which patients acknowledge a set of factors as the cause of the disease and which have the same level of importance is established. There is no connection with lifestyle or work or even reflection on how it can determine the fact they have tuberculosis<sup>(14)</sup>. The view of patients concerning their disease is associated with the context to which they belong. Suffering originates from impotence in the face of a state of affairs in which people are valued by what they are able to produce.

In general, the perceptions of health professionals and patients concerning ST differ in relation to the need of going daily to the health unit and the duration of their treatment. For the first group, these characteristics of DOTS treatment make it difficult for patients to follow because the professionals see that the patients do not like the strategy. However, for the latter, these are not seen as difficulties; on the contrary, for patients these are valued characteristics. The need to daily visit the health unit and the commitment established between both subjects, seem to be the means through which individuals take responsibility for following their treatment.

In fact, the supervision of taking medication is not restricted to observation only. Observation also enables professionals and patients to bond and this relationship persists even after the treatment ceases<sup>(13)</sup>. The studied patients report they find it pleasurable to meet people who value them and that it is a way to be included in society and feel they belong. In situations of social exclusion, which is not rare among people with tuberculosis, this is an opportunity for them to feel safe, valued and cared for<sup>(3,9)</sup>.

In a study carried out in the central region of São Paulo<sup>(3)</sup>, the issue related to supervision is related to the autonomy of patients and includes a debate about human rights, concluding that ST is less restrictive than hospitalization. Ten patients were interviewed in this study, of which only one felt he lost autonomy. This finding was also identified in another study in which only one patient felt obliged to follow the ST.

Therefore, bonding with patients is important because it is a means to better know each individual's situation, facilitating the implementation of actions that strengthen the inclusion of patients, since the majority present diverse levels of social exclusion<sup>(3)</sup>. For instance, the analysis of the implementation of DOTS in some Brazilian regions revealed that the involvement of teams responsible for the ST is essential for the good functioning of the Brazilian Tuberculosis Control Program<sup>(15)</sup>.

Health professionals seem to acknowledge that bonding facilitates treatment adherence and propose alternatives, i.e. allowing flexible hours for taking medication when the patient works. Each professional acknowledges the uniqueness of each patient and proposes alternatives so that ST is not a barrier in patients' daily lives.

The field work allowed us to perceive the need of professionals to be more engaged and willing to work with ST because the professionals' commitment influences the establishment of bonds<sup>(13)</sup>. These aspects are related to the organization of work processes in the health unit and to human resources policy. In a study carried out in nine cities in the state of São Paulo, the lack of human resources, high turnover, professionals' poor qualifications and awareness, and work overload were verified, which lead to a certain resistance to incorporate ST and to actively search for cases, compromising the interaction with patients and the establishment of bonds<sup>(16)</sup>.

The importance of committed professionals working with tuberculosis is highlighted<sup>(13)</sup>. Another study in which interventions that seek to overcome biological and social vulnerabilities, even minimal ones, are among the goals of workers and confer dignity on patients<sup>(12)</sup>.

The WHO recommends that patients choose the health worker who will accompany them during the treatment. The fieldwork revealed that patients seem to identify themselves with only one professional, that one who seems to be more available and reliable. In fact, it facilitates the treatment because patients feel less exposed and safer to express their needs, including overcoming prejudice that might occur in the healthcare service.

A study addressing the attitudes of patients with tuberculosis<sup>(11)</sup> concluded that the health team, especially the nursing team, has a great importance and greatly influences treatment adherence to the extent it is motivated to deliver quality care. In fact, the interviews revealed that almost all professionals

accompanying patients or who were responsible for ST in the health unit belonged to the nursing team. This fact was identified in other studies carried out in Ribeirão Preto and in the West and Central regions of the city of São Paulo<sup>(9,11-13)</sup>.

Patients feel reassured when they acknowledge the team is competent and supports them during the treatment, including exams, consultation for patients themselves and their families, and emergency care. Patients state that this support was not directly offered before the ST.

The monthly consultations are extremely valued by patients, who seek confirmation that their condition improved through exams. It is interesting that patients reproduce the way current clinical practice is concretized, which is mainly based on supplemental exams. Even when the patients experience improvement in their symptoms, it is the exam's result that confirms that one's clinical condition has in fact improved<sup>(11)</sup>. This view, which is encouraged by the media in general, usually does not promote prevention or health promotion, does not evoke in the patients the interpretation that health and disease are associated with the way life and work are processed. The Ottawa Charter states that

Health professionals seem to acknowledge that bonding facilitates treatment adherence and propose alternatives...

[...] Political, economic, social, cultural, environmental, behavioral and biological factors can all favor health or be harmful to it<sup>(17)</sup>, however, the level of importance each factor has on the lives of people is not considered here, which is taken into account by the Social Determination Theory of Health-Disease. This theory states that the way the society is organized determines potential exhaustion or strengthening that act on the health-disease continuum<sup>(14)</sup>.

The incentives provided to patients that follow ST are criticized. Snacks are offered to the majority of patients and bus passes are offered when they need to have an exam at another health service. The incentives have been adopted by several Brazilian cities to facilitate adherence and are assumed to be an alternative for the establishment of bonds with health professionals<sup>(18)</sup>. However, the staple food basket seems to generate embarrassing situations: on the one hand, patients need the basket because of their social and economic situation—in general patients are socially and economically excluded; on the other hand, professionals resent not being totally truthful with patients, since they guarantee the benefit but it is not regularly supplied.

Another study indicates that these incentives are part of a very common ideology in Brazil, which integrates so-called philanthropy<sup>(12)</sup>. The author of this study states that such practice, [...] *not being well managed can result in further exclusion of these patients...* Another study suggests that the heterogeneity of incentive distribution in the city of São Paulo has negative repercussions on the Brazilian Tuberculosis Control Program (TCP) and that ST cannot depend on *arrangements* in which only some sub-districts include patients in the program, while others depend on donations<sup>(3)</sup>. In a study carried out in Ribeirão Preto evaluating the performance of health services in the implementation of DOTS in households, the authors identified the discontinuity of incentives as something that might interfere with adherence<sup>(18)</sup>.

There is a new expectation based on the approval of funding for activities of tuberculosis control in 2005 by the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). This funding might ensure regularity of incentives supply, however, it is worth highlighting that these benefits *per se* will not solve the complex issues involving tuberculosis. The disease is closely associated with social inclusion and, as such, it is necessary that inclusion policies in general be urgently implemented. The TCP has many difficulties in relation to the quality of services supplied, which varies among states due to the process of decentralization. In Rio de Janeiro, for instance, a law that would provide that payment of a monthly incentive for patients was not signed. São Paulo is somewhat a privileged city because the majority of its primary health units have diagnosis services and medication available, and also because it integrates the State Program to Fight AIDS<sup>(17)</sup>.

The DOTS implementation process also lacks physical, human and material resources<sup>(16)</sup>. Some professionals in this

study reported they had sought to overcome such barriers by attempting contact with the coordinators of the program, though they had no response. It is important to note that the *Pact 2004*, established at the time of the TCP, allows financial transfers to cities that achieve a goal of 90% cure.

Despite the fact SUS defends the principle of social participation and control so that the community certifies its expectations and needs are being met by health services, a great instability is evidenced<sup>(15)</sup>. The non-participation of civil society in actions related to tuberculosis limits disease control<sup>(15-16)</sup>. In fact, no initiatives organized by society were mentioned during interviews, even though the literature proposes that considering an intervention capable of incorporating patients' expectations, involvement of families and organized society could contribute to tuberculosis treatment<sup>(19)</sup>. In addition, health work aims to recover the individual and go beyond, contributing to meet all demands that transcend health. This is why there is a need to link sectors and include the community<sup>(2,13)</sup>.

Despite the professionals reporting that patients have difficulty following treatment due to its duration and daily visits to the health unit, they believe in DOTS and base this rationale on the low rates of abandonment in the unit where they work to declare the strategy's problem solving capacity. Professionals also reported that the Health Program facilitates the search for cases and bonding with patients.

It is important to mention that São Paulo was the first state to implement DOTS in part because of the decentralization of its implementation. In 1998, 36 cities adopted the strategy and according to data from 2003, the city had coverage between 10% and 49%, and according to the São Paulo Department of Health, its coverage was a little higher than 18% in 2004 with a great variation when the coefficients of each district are considered. (In *Campo Limpo* it reached 86% and in *Freguesia do Ó/Brasilândia* 35%). The involvement of city health management teams encouraged integrated actions between the TCP with the teams of Family Health Strategy and the Community Health Agents Program (CHAP) in their city network. The CHAs have been important actors in this coordination. They are recognized for their *flexibility* to assimilate new strategies and, especially because they live in the same area as patients, these professionals contribute to the acknowledgement of patients' needs. However, it is also acknowledged that such professionals need to be better prepared and receive support from the Program<sup>(15-16,20)</sup>.

Adherence to ST has been analyzed by many researchers<sup>(1-3,13,15,21)</sup> since the implementation of the DOTS in the state of São Paulo. Many of these researchers concluded that the strategy increases adherence rates and diminishes abandonment.

Schemes of treatments of long duration are in general associated with difficulties in regard to adherence. The reason is that several components related to adherence are difficult to classify because they present interdependency

and subordination relations, of which the following are highlighted: understanding of the health-disease process and individuals' status in addition to the organization of health services, which should focus on patients' needs<sup>(3)</sup>.

This study also identifies aspects that enable adherence. According to the view of patients and professionals, adherence depends on the will of patients to be healed so they can resume their activities, especially to go back to work, which is in general limited or impossible due to the disease.

Adherence is understood as an element that mainly depends on patients<sup>(2,12)</sup>. Consensus was achieved in this study about the importance of family support to the continuity of treatment. However, the support of the health team is also essential as it must be responsible for the supply of information about the disease and reinforcement of the need for treatment. However, bonding seems to be the most important element in the process because it makes the environment friendlier and also allows professionals to know about their patients' daily routines and needs, which enable them to individualize care<sup>(11,13)</sup>.

According to the participants, the resources of the health unit also increase adherence. Among these resources, monthly consultations, exams, and free supply of medication are highlighted. These same results are found in another study and are identified as *strengths* in the development of treatment<sup>(12)</sup>.

As already mentioned, incentives increase adherence due to the patients' poor living conditions. In fact, the majority of the interviewed patients lived in regions, which, according to the map of social inclusion/exclusion of the city of São Paulo, present the highest social risk and are where the state intervenes less<sup>(22)</sup>.

The medications' side effects also influence adherence and that is why health professionals need to be available and show empathy. They need to be able to identify with their patients and refer the situation to another professional or section when they cannot resolve it. This issue is mainly related to the mechanism of action of the medication but also depends on how the patient situates him/herself in relation to the treatment. Thus, health education actions should provide information to patients and empower them so they can overcome the disease process<sup>(12)</sup>.

One last aspect emphasized in this study is that treatment adherence is linked to the inclusion of individuals into

society (to whether they have a structured family, work, live on the streets, are alcoholic, addicted to drugs or have HIV)<sup>(2)</sup>.

## FINAL CONSIDERATIONS

Tuberculosis is a stigmatizing disease that doubly victimizes patients. They have to seek a cure since they consider themselves the one responsible for acquiring the disease and deal with the suffering that accrues from others' prejudice. In general, patients insist on providing a multi-factor cause for the disease, masking the social determination of the process.

In general, both patients and health professionals approve DOTS because, even though it is a difficult path, it seems to ensure a cure, which most of the time means survival and returning to productivity. The supervision of taking medication did not seem to compromise the patients' autonomy, rather it promotes increased inclusion into society since the bond created in the patient-professional interaction brings out significant feelings that contribute to patients' adherence such as: feeling safe and cared for. Autonomy seems to be encouraged, since the relationship favors joint decision-making concerning the relaxation of the treatment, especially when patients keep working.

Apparently, what limits the strategy is the lack of professionals' preparedness to deal with patients and their numerous demands and needs, which go beyond taking medication and improvement of the disease. One has to keep in mind that issues related to the implementation of the strategy, especially the supply of incentives, which are important for patients because of their social exclusion, need to be better organized, systematized and regularized, even though they do not meet the need of social inclusion policies.

Hence, in order to facilitate the implementation of DOTS in the city of São Paulo, this study suggests that knowledge about tuberculosis be more widely disseminated among patients, their families and communities, not as a one-time campaign, but as an ongoing supply of information so as to reduce the disease stigma. For that, professionals need to be sensitized and acknowledge that the way society is organized influences the health and disease of the population with which they work and also need to promote interactions among the various social actors such as schools, neighborhood associations, non-government organizations, sport centers, cultural centers, churches, and businesses that can support disease control.

## REFERENCES

1. Bertolozzi MR. Pacientes com tuberculose pulmonar no Município de Taboão da Serra: perfil representações sobre a assistência prestada nas Unidades Básicas de Saúde [dissertação]. São Paulo: Faculdade de Saúde Pública, Universidade de São Paulo; 1991.
2. Bertolozzi MR. A adesão ao programa de controle de tuberculose no Distrito Sanitário do Butantã [tese]. São Paulo: Faculdade de Saúde Pública, Universidade de São Paulo; 1998.

3. Bertolozzi MR. A adesão ao tratamento da tuberculose na perspectiva da estratégia do Tratamento Diretamente Observado ("DOTS") no Município de São Paulo - SP [tese]. São Paulo: Escola de Enfermagem, Universidade de São Paulo; 2005.
4. World Health Organization (WHO). Global Tuberculosis Control: epidemiology, strategy, financing. WHO report 2009. Geneva; 2009.
5. Villa TCS, Assis EG, Oliveira MF, Arcênio RA, Gonzáles RIC, Palha PF. Cobertura do Tratamento Diretamente Supervisionado (DOTS) da tuberculose no Estado de São Paulo (1998-2004). *Rev Esc Enferm USP*. 2008;42(1):98-104.
6. São Paulo (Cidade). Secretaria Municipal de Saúde. Coordenadoria de Vigilância em Saúde (CONVISA). Informe Técnico: avaliação do Programa de Tuberculose do Município de São Paulo 2005 [texto na Internet]. São Paulo; 2005. [citado 2009 jul. 28]. Disponível em: [http://ww2.prefeitura.sp.gov.br/arquivos/secretarias/saude/vigilancia\\_saude/publicacao\\_covisa/0001/Informe\\_TB\\_dez\\_05.pdf](http://ww2.prefeitura.sp.gov.br/arquivos/secretarias/saude/vigilancia_saude/publicacao_covisa/0001/Informe_TB_dez_05.pdf)
7. Fiorin JL. Elementos de análise do discurso. São Paulo: EDUSP; 1989.
8. Breilh J. Nuevos conceptos y técnicas de investigación: guía pedagógica para um taller de metodología. Quito: CEAS; 1995.
9. Sánchez AIM. O Tratamento Diretamente Supervisionado "DOTS" e a adesão ao tratamento da tuberculose: significados para os trabalhadores de Unidades de Saúde da Região Central do Município de São Paulo/São Paulo – Brasil [tese]. São Paulo: Escola de Enfermagem, Universidade de São Paulo; 2007.
10. Rodrigues ILA, Souza MJ. Representações sociais de clientes sobre a tuberculose: desvendar para melhor cuidar. *Esc Anna Nery Rev Enferm*. 2005;9(1):80-7.
11. Lima AL, Souza FBA, Ferreira GL. Tuberculose: atitudes frente à doença. *Bol Pneumol Sanit*. 2005;13(2):83-90.
12. Vendramini SHF. O tratamento supervisionado no controle da tuberculose em Ribeirão Preto sob a percepção do doente [tese]. Ribeirão Preto: Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo; 2001.
13. Terra F, Bertolozzi MR. Tratamento Diretamente Supervisionado (DOTS) contribui para a adesão ao tratamento da tuberculose? *Rev Lat Am Enferm*. 2008;16(4):659-64.
14. Fonseca RMGS, Bertolozzi MR. A epidemiologia social e a assistência à saúde da população. In: Fonseca RMGS. A Classificação das Práticas de Enfermagem em Saúde Coletiva e o uso da epidemiologia social. Brasília: Associação Brasileira de Enfermagem; 1997. p. 1-26.
15. Ruffino Netto A, Villa TCS, organizadores. Tuberculose: implantação do DOTS em algumas regiões do Brasil: histórico e peculiaridades. Ribeirão Preto: Wdesign e Associados; 2006.
16. Monroe AA, Cardoso Gonzales RI, Palha PF, Sassaqui CM, Ruffino Netto A, Vendramini SHF, et al. Envolvimento de equipes da atenção básica à saúde no controle da tuberculose. *Rev Esc Enferm USP*. 2008;42(2):262-7.
17. Pedrazzini ES. Doenças reemergentes: a formação de recursos humanos para o seu enfrentamento. *Acta Paul Enferm*. 2000;30(n.esp):123-30.
18. Cardozo Gonzales RI, Monroe AA, Assis EG, Palha PF, Villa TCS, Ruffino Netto A. Desempenho de serviços de saúde no tratamento diretamente observado no domicílio para controle da tuberculose. *Rev Esc Enferm USP*. 2008;42(4):628-34.
19. Santos FET, Gomes ZMS. Estratégias de controle da tuberculose no Brasil: articulação e participação da sociedade civil. *Rev Saúde Pública* 2007;41 Supl. 1:111-6.
20. Maciel ELN, Vieira RCA, Milani EC, Brasil M, Fregona G, Dietze R. O Agente Comunitário de Saúde no controle da tuberculose: conhecimento e percepções. *Cad Saúde Pública*. 2008;24(6):1377-86.
21. Vendramini SHF, Gazetta CE, Chiaravalotti Neto F, Cury MR, Meirelles EB, Kuyumjian FG, et al. Tuberculose em município de porte médio do Sudeste do Brasil: indicadores de morbidade e mortalidade, de 1985 a 2003. *J Bras Pneumol*. 2005;31(3):237-43.
22. Sposati A, coordenadora. Que cidade é esta? São Paulo: Núcleo de Segurança e Assistência Social da PUC/SP; 1997.