

## The families and directly observed treatment of tuberculosis: senses and prospects to the production of care



*Famílias e o tratamento diretamente observado da tuberculose: sentidos e perspectivas para produção do cuidado*

*Las familias y el tratamiento directamente observado de la tuberculosis: sentidos y perspectivas para la producción del cuidado*

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### ABSTRACT

The purpose was to identify the families' participation on care management of patients with tuberculosis. Also, to ascertain the contribution offered by health professionals for patients' families with ongoing treatment, and investigate the importance attributed by the families to the directly observed treatment. It is a descriptive, cross-sectional study conducted in the municipality of Ribeirão Preto/SP with families of patients diagnosed with tuberculosis. For data collection, it was developed an instrument that underwent pretesting and content validation. Ninety four subjects were interviewed. According to the results, 64 (68.0%) relatives participated in the care management and 81 (86.2%) reported a good relationship with the staff. Sixty three family members (67%) did not receive any guidance about drugs and 75 (80.0%) of the respondents considered the strategy as relevant. The findings indicate that the Directly Observed Treatment has limitations regarding the guidelines of clinical management of the disease, the inclusion of family in care management and understanding of its goals.

**Descriptors:** Family relations. Directly observed therapy. Tuberculosis.

### RESUMO

O objetivo foi identificar a participação das famílias na gestão do cuidado do doente de tuberculose, o aporte oferecido pelos profissionais de saúde às famílias de doentes em tratamento e a importância atribuída pelas famílias ao Tratamento Diretamente Observado. Trata-se de um estudo descritivo de corte transversal, realizado no município de Ribeirão Preto, SP, junto às famílias dos pacientes diagnosticados de tuberculose. Para coleta de dados, foi elaborado um instrumento que passou pela validação de conteúdo e pré-teste. Foram entrevistados 94 sujeitos. Nos resultados, 64 (68,0%) dos familiares participaram da gestão do cuidado, 81 (86,2%) relataram boa relação com a equipe, 63 (67%) não receberam orientação dos medicamentos e 75 (80,0%) consideraram a estratégia como relevante. Os achados do estudo apontam que o Tratamento Diretamente Observado apresenta ainda limitações quanto às orientações do manejo clínico da doença, a inclusão da família na gestão do cuidado e na compreensão dos seus objetivos.

**Descritores:** Relações familiares. Terapia diretamente observada. Tuberculose.

### RESUMEN

El objetivo fue identificar la participación de familiares en la gestión del cuidado del enfermo con tuberculosis, averiguar el aporte de los profesionales de la salud para las familias de pacientes en tratamiento e investigar la importancia atribuida por esas familias al tratamiento directamente observado. Estudio descriptivo, corte transversal y realizado en el municipio de Ribeirão Preto/SP con las familias de pacientes diagnosticados con tuberculosis. Para obtener los datos fue elaborado un instrumento que pasó por la validación del contenido y preexamen. Fueron entrevistados 94 sujetos. De acuerdo con los resultados, 64 (68,0%) de los familiares participaron de la gestión del cuidado; 81 (86,2%) relataron una buena relación con el equipo, 63 (67%) no recibieron orientación sobre medicamentos y 75 (80,0%) consideraron la estrategia como relevante. Los resultados señalan que el Tratamiento Directamente Observado presenta limitaciones sobre las orientaciones del manejo clínico de la enfermedad, la inclusión de la familia en la gestión del cuidado y en la comprensión de los objetivos.

**Descriptores:** Relaciones familiares. Terapia por observación directa. Tuberculosis.

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## ■ INTRODUCTION

One of the world's oldest infectious diseases, tuberculosis (TB) remains an issue of global concern. According to data of the World Health Organization (WHO), 5.8 million new cases and 1.4 million deaths from the disease were reported in 2011. Brazil ranks 17th among the 22 countries that account for 80% of the cases of tuberculosis in the world<sup>(1)</sup>.

With the purpose of significantly impact the epidemiology of tuberculosis, several measures were launched by Brazilian authorities, including the increase in the coverage and sustainability of the Directly Observed Treatment (DOT) in health care service systems. The DOT consists in the monitoring of drug intake by TB patient, either by the health professionals, community health workers or community members and families<sup>(2)</sup>.

Despite being an important political guideline for the management of disease control, there is still disagreement in the scientific literature regarding the effectiveness of the strategy in fighting tuberculosis and breaking the chain of transmission<sup>(3-4)</sup>.

According to the authors, it has not been possible to demonstrate the impact of DOT in reducing treatment failures and MDR-TB multidrug-resistant tuberculosis. Besides, the authors observed that the effectiveness of the strategy directly depends on its *modus operandi* and sensitivity in order to understand and interact with each other. Thus, the main determining factor for adherence to tuberculosis treatment has been associated to the interaction between professionals and subjects<sup>(3-4)</sup>.

On the other hand, there are some characteristics especially stressed in the literature<sup>(5-6)</sup> that are inherent to the success of the DOT such as bond, listening, co-responsibility and construction of therapeutic processes that include the families. Particularly regarding the latter, there are no studies focused on the families or aimed to investigate the interaction between these actors and the health professionals themselves.

The same is observed for possible variables that interfere in the quality of this interaction, and, thus, in the legitimacy and recognition of DOT by the families. Although markers have been set for the quality of care in TB in Brazil<sup>(6)</sup>, no other study focused on the prospect of care production by families as a parameter to assess DOT practices and, thus, technology.

For the purposes of the study, the definition of care is based on a classical research<sup>(7)</sup>, which defines it as the vector of the subjective relationships and that adds many components, with emphasis to the main role played by the

subjects and the recognition of social and individual needs, which should be met to ensure proper health care.

Also, since the families are the bond between the patients and the health care service, they deserve a special consideration of governmental policies on health care and social protection<sup>(8)</sup>. The family plays a key role in the context of collective health, for they provide an overview of the dilemmas faced by patients after being diagnosed with TB and of the changes produced by such diagnosis within the family context<sup>(9)</sup>.

Therefore, the present investigation aimed to identify the participation of the families in the management of care to TB patients, assess the contribution of health care professionals to patients' families and find out the importance attached by families to the DOT. For the purposes of this study, the management of care, in the family dimension, was considered the supply or provision of health technologies, according to the specific needs of everyone on several occasions of life, seeking their welfare, safety and autonomy, to ensure a productive life<sup>(10)</sup>.

## ■ MATERIALS AND METHODS

This is a quantitative, descriptive, cross-sectional study conducted with families of patients diagnosed with TB resident in the city of Ribeirão Preto (SP), which has a population of approximately 604.682 inhabitants and is considered a reference to surrounding cities, regarding technology levels, besides being considered a priority city for efforts to control TB in the state of São Paulo.

The reference population for the study was composed of family members and persons who lived with TB patients in DOT diagnosed between January 1st, 2010 and July 31, 2011, and identified as part of the System of Control of Patients with Tuberculosis (TBWEB) of the city of Ribeirão Preto. This population was chosen for the following reasons: a) they were close to the TB patient, thus, belonging to their nuclear family; b) Since the patients were recently diagnosed with TB, it would be easy to locate these individuals at the addresses informed during the completion of the compulsory notification forms and other records of the Program of TB Control (PCT); c) Limit memory biases, justifying the selection of a cohort of patients diagnosed over the past two years. Thus, as previously mentioned, people of both sexes, aged 18 or over at the time of collection, resident in Ribeirão Preto-SP, and who were available for the interviews were selected.

Patients who did not live with their families, who were hospitalized in long-stay institutions or who were not at home after three attempts of researchers.

The method used was a simple random sample without replacement to ensure the representativeness of the research data. The selection was proportional to the reference population. Thus, the sample size was estimated for finite populations, with a confidence level of 95% and tolerable sampling error of 5%, and the final sample had 94 subjects.

For data collection an instrument with 65 items of closed and open questions was elaborated. The closed questions were presented containing five-point Likert items (1 = never; 2 = almost never; 3 = sometimes; 4 = often and 5 = always) where the patients informed how often they perceived the occurrence of a given event, as well as ordinary and polytomous variables. Then, the instrument went through a process of content validation, being examined by 10 experts who made suggestions regarding its structure and content. Later, a pilot test of the instrument was performed with 10 family members of TB patients who were not included in the final survey. These steps were important to test the questionnaire for cultural sensitivity and check whether it could be easily understood by the reference population for the study.

Then, the researchers listed all the patients diagnosed in the research period from the TBWEB and randomly selected the subjects using Statistical Package for Social Sciences (SPSS) until obtaining a minimal sample. The process of location of the addresses began at that time.

Data collection occurred between July 25 and August 31, 2011. For analysis of data, a database was elaborated using independent double data entry in Excel. After validation, data analysis was performed with software SPSS for Mac and STATISTICA 9.0 of StatSoft®.

Univariate and bivariate analysis were performed for checking the association between the importance or non-importance of DOT referred by the family members (dependent variable) and the other independent variables. In the bivariate analysis, the researchers crossed the dependent dichotomous variable with each of the independent variables, according to their nature, by means of contingency tables (chi-square test, chi-square test with Yates correction or Fisher exact test). Descriptive statistics was also performed, with calculation of position measurements (mean and median) and dispersion measurements (standard deviation).

The project was approved by the Research Ethics Committee of the School of Nursing of the University of São Paulo (Protocol number 1292/2011), with observance PF ethical and legal aspects of the research on humans, recommended by Resolution No 196/96 of the Brazilian National Health Council<sup>(11)</sup>.

## ■ RESULTS

Of the 94 family members interviewed, 73 (77.7%) were female and 21 (22.3%) were male. The minimum age was 18 and the maximum was 84, with a mean age of 49 years. Regarding schooling, 53 (56.4%) completed elementary school, 26 (27.7%) completed secondary school, five (5.3%) completed higher education and ten (10.6%) had no schooling. Regarding occupation, 19 (20.2%) were informally employed and 63 (67.0%) had a family income ranging from two to four minimum wages.

Concerning the profile of family members, 64 (68.0%) of them participated in the management of care; most were female, aged 30 to 59 years, with elementary education, informally employed and with an income of two to four minimum wages (Table 1).

Regarding the objective of investigating the contribution of health professionals it is important to clarify that it was assessed according to two dimensions: the professional-user interaction and the care provided by health professionals to TB patients.

In professional-user interaction, 81 (86.2%) of the respondents reported having a good relationship with health professionals and 13 (13.8%) said this relationship was unsatisfactory. As for the variable care received, 63 (67.0%) of the total family members did not receive any guidance on the types of drugs used in the treatment, as well as on their action and possible adverse effects.

In Table 2 it can be seen that the variables aged 50 or older, satisfactory team-user interaction and the inclusion of family in the planning of care showed association with statistical significance regarding the importance attached by families to DOT.

Finally, in the assessment of the importance of DOT according to the family members of TB patients, it was found that 75 (80.0%) of the respondents considered this activity relevant and 19 (20.0%) said DOT was not related to the success of treatment. Also, they were unable to provide information on the DOT, and did not feel valued or involved in the development of the treatment.

## ■ DISCUSSION

Based on the proposal to investigate the participation of families in the DOT, the contributions provided by health professionals to these actors and the importance attached by families to the DOT, the findings obtained indicate that most family members were involved in the strategy and recognize its importance for the recovery and rehabilitation of the patient. Among the possible variables associated to

**Table 1.** Participation of families in the management of care, according to the sociodemographic characteristics of the family members of patients with tuberculosis in Ribeirão Preto (SP), 2011.

Variables	Participation of families in the management of care			
	Yes		No	
	n (64)	%	n (30)	%
Sex				
Female	50	78.1	23	76.7
Male	14	21.9	7	23.3
Age				
≤ 30 years	9	14.1	6	20.0
30  –  50 years	41	64.0	14	46.7
≥60 years	14	21.9	10	33.3
Schooling				
No schooling	6	9.4	4	13.3
Elementary School	33	51.6	20	66.7
Secondary School	20	31.3	6	20.0
Higher Education	5	7.7	0	0.0
Occupation				
Unemployed	6	9.4	5	16.7
Household tasks	15	23.4	5	16.7
Retired and pensioner	13	20.3	9	29.9
Formal employment	16	25.0	6	20.0
Informal employment	14	21.9	5	16.7
Family Income				
≤ 1 minimum wage*	14	21.9	8	26.7
1  –  4 minimum wages	42	65.6	21	70.0
≥ 5 minimum wages	8	12.5	1	3.3

Source: Research data.

Note: \* Minimum wage as of 2011 (value of R\$ 600,00).

this perception of importance are old age, professional-user interaction, satisfactory professional-user interaction and inclusion of family in the production of care.

Analysis of the sociodemographic characteristics of family members showed that, as reported in the literature<sup>(12)</sup> the caregivers who assisted TB patients were predominantly female, in economically productive age.

A study conducted in Maceió – AL<sup>(13)</sup> confirms that there is a female provision in family care, since this is based in values passed from generation to generation. However, the authors<sup>(14)</sup> report that the larger the family bond, the greater the emotional burden involved in any process of sickness and health.

Regarding the occupation, most family members/caregivers were retired, pensioners or informally employed, which is consistent with a study conducted with patients suffering from a different illness in Fortaleza-CE<sup>(14)</sup>. Informality may be directly associated to precarious jobs, besides being considered one of the main characteristics of impoverishment and increased unemployment in peripheral countries, such as Brazil<sup>(15)</sup>.

Regarding schooling, it can be seen that the family members of TB patients, as well as caregivers of patients with other conditions had completed only secondary education<sup>(13)</sup>. The prevalence of TB is related to low levels of education and is also the risk factor that most contributes

**Table 2.** Possible variables associated to the importance attached to the Directly Observed Treatment by families of TB patients. Ribeirão Preto (SP), 2011.

Variables	Importance of Directly Observed Treatment				P Value
	No n (9)	%	Yes n (85)	%	
Sex					
Female	6	6.4	67	71.3	0.321
Male	3	3.2	18	19.1	
Age					
≤ 50	8	8.5	40	42.5	0.041*
≥ 50	1	1.1	45	47.9	
Professional-user interaction					
Unsatisfactory	4	4.2	9	9.6	0.019*
Satisfactory	5	5.3	76	80.9	
Health care team provides guidance on drugs					
Yes	5	5.3	26	27.7	0.128
No	4	4.2	59	62.8	
Family members of the patient were examined					
Yes	6	6.4	59	61.7	0.567
No	3	3.2	26	28.7	
Escorts the family member to the health service					
Yes	6	6.4	58	61.7	0.779
No	3	3.2	27	28.7	
The health team includes the family in patient care					
Yes	3	3.2	61	64.9	0.027*
No	6	6.4	24	25.5	
Observes the family member taking the medication					
Yes	5	5.3	57	60.6	0.363
No	4	4.3	28	29.8	

Source: Research data

Note: \*P < 0.05. Chi-square test, chi-square test with Yates correction or Fisher exact test

to non-adherence to treatment or delayed diagnosis, generating a set of socioeconomic conditions that increase social vulnerability to TB and are the main factors responsible for the high incidence of the disease<sup>(16)</sup>.

On the other hand, the results obtained indicate that the families are participating in the management of care to TB patients. For some authors, the family is the most important microstructure in the constitution of representations and practices of subjects in relation to their health-disease-care process<sup>(10)</sup>. In the context of TB, the family is more than mere consanguinity, because in most cases it shares the responsibility for adherence to treatment<sup>(13)</sup>.

This is the case of DOT, once the professional has a caring attitude, listening to all the involved individuals, identifying the needs expressed by the patient and family members, in order to define with them the best strategies to manage TB treatment, i.e., creating a process of co-responsibility<sup>(17)</sup>.

In a study carried out in London, the patients expressed their satisfaction with TB services, especially in what concerns communication and organization of the services. Moreover, they noticed that the patients were motivated to proceed with the treatment because of the bond established between them and the professionals. In

fact, the patients did not want to disappoint their “new” friends, despite the great difficulty in adhering to treatment and the large number of drugs to be taken, as well as their adverse effects.<sup>(18)</sup>

Although the results indicated that most family members considered DOT activity as satisfactory, 20% of the respondents said that DOT was not related to the success of treatment and that they did not feel involved or valued while in the treatment.

There are reports of arbitrary measures, of imposition of the DOT in the scientific literature, causing many patients to travel long distances to reach the health services, suffering financial and social damage. There are reports of patients who lost their jobs because of these strict and non-negotiable measures.<sup>(19)</sup>

Thus, we can question the effectiveness of DOT, because being inserted in this type of treatment did not ensure collective actions of health education, once the subjects reported that they did not receive guidance on the drug used during the treatment, and some of them were afraid and felt uncomfortable to discuss the topic during the interviews, maybe because some aspects, such as the stigma of the disease, were not being discussed in the meetings with the families.

Although the study showed important markers set for the quality of DOT in the production of care to TB patients and their families, it should be mentioned that there were some limitations, such as the difficulty of family members to understand the importance of DOT, given that the interviewers were introduced to the patients by the health professionals; the memory bias, of forgetting some event in the past, since the families were not systematically monitored, with the results being established according to the responses to the instrument, and finally the limitation of the instrument itself, which was subjected only to content validation. However, the present study has made it possible to identify new prospects for studies that possibly pointed to innovative actions for the control of TB in the country.

## ■ CONCLUSION

Most family members who participated in the management of care to TB patients have sociodemographic characteristics similar to those of family members of patients with different illnesses. Informal employment and low family income being the main characteristics of this population.

It was observed that some family members were not informed on the clinical management of the disease, which

was attested by the high number of individuals who did not receive information on the drugs used in the treatment.

Statistical analyzes showed that the variables aged 50 or older, satisfactory team-user interaction and inclusion of the family in the production of care showed a significant association with recognition/importance attached by families to DOT.

Therefore, the findings of the present study indicate that, although most family members are aware of the importance of DOT, this still has some limitations regarding the clinical management of the disease, inclusion of family in the management of care and the understanding of its purposes.

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