KNOWLEDGE AND PERCEPTION ABOUT TUBERCULOSIS OF PATIENTS' FAMILIES UNDER DIRECTLY OBSERVED TREATMENT AT A HEALTH SERVICE IN RIBEIRÃO PRETO-SP, BRAZIL[1]

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ABSTRACT: The aim of this descriptive and epidemiological research was to describe the demographic profile of patients´ families who are under Directly Observed Treatment at a health service, in Ribeirão Preto, Brazil. To analyze the context they were inserted in by considering parenthood and clinical-epidemiological aspects of the family member with tuberculosis, and to assess these families' knowledge and perception about tuberculosis. Data were collected in July 2010, by using a semistructured questionnaire that was applied to 16 family members. Descriptive statistics were used for data analysis. The families' demographic profile supports the association among tuberculosis, conditions of poverty and low income distribution. A substantial number of patients with pulmonary tuberculosis as the predominant clinical form was found at their homes. The families' knowledge was satisfactory, but some subjects associate the transmission of the disease with the shared use of domestic utensils. The results appoint weaknesses related to the families´ care management.

DESCRIPTORS: Tuberculosis. Knowledge. Family relations.

CONOCIMIENTO Y PERCEPCIÓN DE LAS FAMILIAS SOBRE TUBERCULOSIS EN PACIENTES BAJO TRATAMIENTO DIRECTAMENTE OBSERVADO EN UN SERVICIO DE SALUD DE RIBEIRÃO PRETO-SP, BRASIL

RESUMEN: Investigación epidemiológica con objetivo de describir el perfil demográfico de familias de pacientes en Tratamiento Directamente Observado en un servicio de salud de Ribeirão Preto, Brazil, analizar el contexto en que estaban inseridas, respecto al grado de parentesco y aspectos clínico-epidemiológicos del familiar con tuberculosis, y evaluar el conocimiento y la percepción de esas familias respecto a la tuberculosis. Los datos fueron recolectados en julio del 2010, utilizándose un cuestionario semi-estructurado con 16 familiares, siendo analizados mediante estadística descriptiva. El perfil demográfico corrobora la asociación de la tuberculosis con condiciones de pobreza y mala distribución de renta. Se verificó un número substancial de comunicantes en domicilio, siendo la tuberculosis pulmonar la forma clínica predominante. El conocimiento de las familias fue satisfactorio, pero algunos sujetos asocian la transmisión de la enfermedad al uso compartido de utensilios domésticos. Los resultados indican fragilidades en la gestión del cuidado a las familias.

DESCRITORES: Tuberculose. Conhecimento. Relações familiares.

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DESCRIPTORES: Tuberculosis. Conocimiento. Relaciones familiares.

INTRODUCTION

The family is the first instance on health care and the most significant microstructure of people´s representations definition and decision making in relation to the health/disease process. Thus, the ways families are situated in relation to the disease or how they perceive it are important determinants for their choices and behaviors.[1-2]

Since the 1970s, after the crisis of the Welfare State, the figure of the family gained strength as social protection system and structure of "recovery and support" of social solidarity, raising health practices for a movement giving priority to the family counseling.[2]

In attention to the tuberculosis (TB), the family nucleus inclusion has been gradual and differentiated among countries, varying with the degree of organization and centrality of health policies focused on the family. Literature studies showed that in comparison to the TB patient, it may take two central roles: to be the source of support and assistance in coping with the disease and its treatment completion[3-5] or even abandon the patient by segregation or insulation against the disease.[6-8]

On a research conducted in the municipality of Chongqing, China, the authors identified although many patients are aware of TB cure, they were disappointed and discouraged at the time of diagnosis due to the possibility of families' reprisal. So, they were forced to delay the treatment or even omit the diagnostic result to their families.[9] Other investigations also reported the TB patient showed different ways to consider the disease,[10] different interpretations about feeling ill,[11-13] but little importance on the perception of the family about the illness,[14] despite the importance given to the health care management.

Clearly, the proposal to look for the family, in search of understanding about the challenges on TB care at the health services network, is well justified in the very conception that it has an important role in legitimizing the disease, demanding for services health and ways to treat it. Some authors[1] consider this social institution as a more appropriate study object to understand the phenomena generating the disease, subjects´ therapeutic choices and enabling expanded understanding on the health/disease process. Thus, it is possible to have more controlled health services organization by the family units' singularities.

This situation is part of the social policy on Directly Observed Treatment (DOT), which according to the World Health Organization (WHO), should be strengthened through established partnerships with the family nucleus and community. It is emphasized the DOT strategy was recommended, in 1993, as a device for ensuring pharmacological therapeutic regularity when TB was declared as global emergency. It became a monitoring technology of medications intake, in which the TB patient might be supervised by a health professional, his family or even community volunteers during drug therapy. In São Paulo, it is observed that the increase of this strategy has resulted in significant reduction of treatment abandonment rates.[3]

Considering the presented information, it is possible to say that families´ knowledge and perception are essential conditions to formulate effective health policies to combat the disease. The manuscript was performed to describe the families´ demographic profile of patients in DOT at a health service, in Ribeirão Preto-SP. To analyze the context in which these families were inserted by considering their kinship and clinical-epidemio-

logical aspects of the patients with TB, in order to evaluate families´ knowledge and awareness in relation to the disease.

METHODS

In this study, it was used a cross-sectional design. The investigation was conducted in the municipality of Ribeirão Preto-SP, which is organized into five health districts (north, south, east, west and central), and the attention for TB patients is provided at the secondary level in the five health services that have Tuberculosis Control Program (TCP). They operate with specialized teams and perform actions for the diagnosis and clinical management of cases and patients.

The service choice to the study setting, which is located in the western district, was due to the geographic ease for access and the ties already established between users and health professionals. Also, it should be noted in that service, the DOT is predominantly held at patients´ homes through visits occurring in the morning, and with an average of five visits per day.

The reference population consisted of patients´ relatives diagnosed with TB, between January 1 and July 31 2010, and following the DOT. It was selected subjects of both sexes, TB patients aged 18 or more years old at the collection time, residing in Ribeirão Preto and who agreed to participate voluntarily in the research by signing the free consent term.

Patients´ relatives who were not following the DOT, submitted discharge from treatment, were hospitalized at the time of collection, did not manifest any conditions to decide on the relative´s participation in the study, living alone, were in shelters or hospitals and were not located at their homes after three visits performed by the researchers were excluded from the investigation.

Of out 31 patients enrolled in the service, only 16 of their relatives met the criteria and constituted the study sample. It is worth noting the interviews with these subjects were conducted predominantly at their homes, and only one them occurred after the patient´s consultation at the service itself, due to the availability provided by the relative.

Data collection was carried out in July 2010. It was used a semistructured questionnaire with 40 items that had been pre-tested in another population, and met the same inclusion and exclusion criteria of the study. The questionnaire consisted of closed and open questions and it was based on another study.[3]

Variables collected are related to demographic characteristics (sex, occupation, income, education), relationship with the TB patient and clinical-epidemiological information (number of patients, treatment duration, clinical shape, associated diseases and time between symptoms onset and diagnosis). In order to assess families´ perceptions and knowledge about TB, the variables considered were dichotomous, polytomous and qualitative in nature. It is noteworthy they were directed to the cause of disease by TB, the period of transmissibility after treatment initiation, appropriate period of treatment (duration), TB curability and concern constancy about contracting TB. Also, it was made a question: "what do you feel by living with a TB patient?" For that question, it was measured the responses frequency. The most prevalent ones were analyzed together with other qualitative variables investigated in the research.

Questionnaires were reviewed, coded and typed in double entry, generating a database in Excel. Data analysis was performed by using the program *Statsoft Statistica*, version 9.0. It was performed the descriptive analysis of the main factors assessed from knowledge and perception, considering the frequency measures, proportions and central tendency (mean, median and mode) and dispersion (standard deviation).

The study was approved by the Scientific Direction of the Health Unit and by the Ethics Committee in Research of the Medicine Faculty of Ribeirão Preto/USP (Protocol Nº 387), in 2010.

RESULTS

Data regarding demographic profile of the study subjects and their relationship with the TB patient are described in Table 1. In that table, it is observed there was a predominance of females (14-87.5%). Regarding age, the participants' average was 53 years, median 55 years, mode 74 years and standard deviation 20 years. Regarding occupation, only one individual (6.25%) was unemployed. As for families' income, the average was 1.9 minimum wages (MW), minimum of one MW, maximum of five MWs and standard deviation of 1.34 MWs. Still, it was verified that six interviewed subjects (37,5%) had no schooling and other six (37.5%) had elementary school. On the kinship degree, it was found that six were wives (37.5%) and the other six were mothers (37.5%) of the TB patients.

Table 1 – Demographic profile of relatives and kinship with TB patients on directly observed treatment at a health service in Ribeirão Preto-SP, 2010

Variables	n	% (n=16)
Age		
< 30 years	2	12.50
30 |-|59	7	43.75
≥ 60 years	7	43.75
Sex		
Male	2	12.50
Female	14	87.50
Occupation		
Self-employed	4	25.00
Housemaid	1	6.25
Salesperson	1	6.25
Nursing assistant	2	12.50
Retiree	5	31.25
Housewife	2	2.50
Unemployed	1	6.25
Income (*)		
≤ 1 minimum wage	10	62.50
1-|4,9 minimum wages	4	25.00
≥ 5 minimum wages	2	12.50
Education		
No schooling	6	37.50
Elementary school	6	37.50
High school	2	12.50
Higher education	2	12,50
Kinship		
Grandparents	2	12.50
Mother	6	37.50
Sister	1	6.25
Wife	6	37.50
Father	1	6.25

(*) The minimum wage at the time of data collection was R$ 560,00 (reals).

With regard to clinical- epidemiological information presented in Table 2, it can be concluded that patients lived, on average, with two or five people (56.25%). The time of treatment of TB patients had an average of 103 days, median 92 days, minimum 25 days and maximum 266 days, with standard deviation of 68 days. The predominant clinical form was pulmonary TB (93,75%) and the associated disease was AIDS (18,75%). With regard to the time between symptoms onset and diagnosis, 68.75% of TB index cases were diagnosed within 30 days after the symptoms onset. However, in one case, the interval exceeded six months. In relation to this variable, it was possible to verify an average of 44 days, median of 30 days and standard deviation of 47 days.

Table 2 - Clinical-epidemiological information of TB index cases on directly observed treatment at a health service in Ribeirão Preto-SP, 2010

Clinical-epidemiological information	n	% (n=16)
Patient number		
≤ 2	2	12.50
2 -|5	9	56.25
5-|9	3	18.75
≥10	2	12.50
Time of treatment		
≤ 2 months	7	43.75
2 -6 months	7	43.75
≥ 6 months	2	12.50
Clinical form		
Pulmonary	15	93.75
Extrapulmonary	1	6.25
Associated diseases		
AIDS	3	18.75
Diabetes and hepatitis	1	6.25
None	12	75.00
Time between symptoms onset and diagnosis		
≤15 days	5	31.25
15-| 30 days	6	37.50
30-| 60 days	2	12.50
60-| 90 days	1	6.25
90-| 179 days	1	6.25
≥ 180 days	1	6.25

In Table 3, it can be seen that 81.25% of the subjects recognized low immunity as TB illness cause. Only 18.75% of the relatives answered correctly on the period of disease transmissibility after treatment initiation, however, about the treatment time, only 43.75% of the subjects gave a correct answer.

In relation to the cure of TB, 87 people (25%) recognize it as a curable disease, however, it was

verified that 50% of the subjects reported their relative was ashamed for being a TB patient. Also, it is noteworthy that 56.25% of the families were not concerned about contracting the disease, but they expressed fear and sadness in the coexistence with the TB patient.

Table 3 - Knowledge and perception about TB of the patients´ families on directly observed treatment at a health service in Ribeirão Preto-SP, 2010

Knowledge and perception	n	%(n=16)
Main cause of illness due to TB		
Low immunity	13	81.25
By air	1	6.25
Strong flu without treatment	1	6.25
Blood	1	6.25
Transmission period after treatment initiation		
Hits (14-15 days)	3	18.75
Errors	9	56.25
Do not know	4	25.00
Treatment time		
< 6 months	1	6.25
6 months	7	43.75
> 6 months	5	31.25
Do not know	3	18.75
TB is curable		
Yes	14	87.25
No	2	12.50
Concern about contracting TB		
A lot	3	18.75
A little	4	25.00
Not concerned	9	56.25
Patient feels ashamed of having TB		
Never/almost never	8	50.00
Almost always/always	8	50.00
Patient told his boss he has got TB		
No	2	12.50
Yes	6	37.50
Ignored (TB patient does not work)	8	50.00
One word to express familiarity with a TB patient		
Fear	8	50.00
Sadness	2	12.50
Others (pity, surprise, indiference)	6	37.50

In Figure 1, cough for more than three weeks, weight loss and inappetence were the symptoms presented by the subjects as tuberculosis suggestive, while night sweat was the least recognized symptom, although 25% of family members did not associate chronic cough with TB.

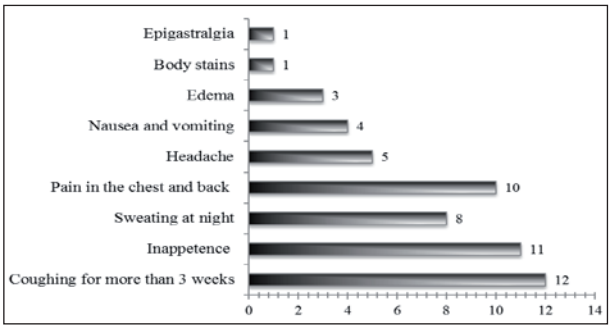

Figure 1 - Absolute frequency of TB common symptoms pointed out by patients´ families on directly observed treatment at a health service in Ribeirão Preto-SP, 2010

As for the disease transmission mode, it was observed that many families associate TB to the use of shared dishes, cutlery and glasses (43.7%). Contaminated water and food were also mentioned as causal factors for TB, although most of them recognize the transmission occurs with respiratory symptoms like cough or sneeze (Figure 2).

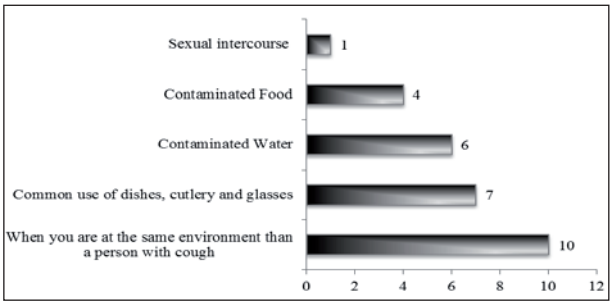

Figure 2 - Absolute frequency of TB transmission forms recognized by patients´ family members on directly observed treatment at a health service in Ribeirão Preto, SP, 2010

DISCUSSION

The demographic profile of the subjects who participate in this study like predominance of feminine gender, age over 30 years, retired people and people whose families lived with incomes lower than a MW are consistent with data from other

investigations that are present in the scientific literature,[6,12,15-18] about TB association with poverty conditions and unequal income distribution. With regard to clinical-epidemiological findings, they showed a substantial number of patients at home, and pulmonary TB was the most predominant and transmissible clinical form.

Families´ knowledge about TB was considered satisfactory, taking into account the majority of respondents referred correctly to the predisposing factor to get ill, transmission mode and disease symptoms. This knowledge, in turn, may be due to the learning built with the health team during the DOT, when families are accompanied by a considerable period of time, receiving constant visits from a professional and the activities on health education are developed.[3,19] Researches show the DOT effectiveness on reducing TB in the communities, when there is a qualified hearing of the patient complaints and his family,[20] through the rescue of these 20 subjects by the establishment of singular therapeutic projects.[18,21]

However, some respondents associate disease transmission form to the sharing of clothes and cutlery, contaminated food and sexual intercourse. Although these individuals represent the minority, the perception of this group should be considered by the health team on care management for the TB patient and his family, because they could provoke postures of segregation and isolation against the disease like other studies indicate.[6,19] The situation found leads the authors to reflect on the TB problem in the studied context. Even with the investment of DOT, the meaning attributed to the disease is still imbued with beliefs and values that are culturally constructed, [22] coming into conflict, at times, with the biological reference that ends up relegating any non-scientific knowledge.

In order to care for TB, it is necessary to change the traditional model that is still in force. It is focused on the disease, the individual, a dialogic model that recognizes the subject as bearer of knowledge and, although different from the technical-scientific knowledge, can not be delegitimized by the services. A new model envisioned for the health agenda would have as prerogative not to inform the social actors, but the transformation of their knowledge, seeking for autonomy and responsibility on health care.[23]

Accordingly, the DOT, whose formulation occurred in the mid-90s, should be reformed today. It should introduce new technologies not only to add knowledge, but also to transform and enhance knowledge acquired in the life history of those subjects.

In relation to the transmissibility period, it was found that most of the subjects were wrong in their responses or they did not know the precise period. In the inquiry concerning treatment duration, they also presented distorted data, and some reported a period of less than 6 months. The literature brings as one of the predictor factors for abandonment, lack of clarification by the health team about treatment time.[6]

Although a number of subjects expressed no concern about contracting TB, they revealed their relatives feel shame of having the disease. This information is clear indicator of social stigma, and the authors consider it as a major challenge to control the disease. Such a fact virtually requires measures that go beyond the biological body and move toward changes in values, ideologies and conceptions of society.

Study shows the stigma and resulting discrimination has a double impact on TB control. The first one refers to the concepts about TB, leading many individuals to defer their visit to the services due to fear of diagnosis or the negative representation of the disease in the community. So, they deny their diseased condition. Due to diagnosis delay, these individuals may develop more severe symptoms of the disease that are more difficult to treat, and they might infect many individuals in the community. Second, during the treatment many individuals are afraid of being identified as "TB" patients in health services and by the community members. Then, they abandon the treatment and favor the development of resistant-multidrug[17] strain.

It is worth noting TB was perceived by the families as a disease that can affect all their members, and even compromise their social relations. A study[15] showed that although there is an idealization of the right behavior with the TB patient, nowadays, narratives have ratified various constraints and conflicts experienced by families in the community.

The authors emphasize although patients make efforts to manage a problem affecting the social relations, it prevails in each individual a deep self-esteem weakening, expressing resignation attitudes towards the disease, and justifying the grief of those families facing the expression to decode the coexistence with a TB patient.

This research brings important aspects that need to be considered in the care plan of the teams,

which refer to the inclusion of families. This is how the TB patient finds strength and support for his rehabilitation, and when he does not feel supported he could give up the therapy and himself.[15] The focus of health policy, in Brazil, has favored the establishment of therapeutic projects that consider the family in the clinical management, but this study reveals some barriers in the reality of the proposal.

For a new reality on TB control, there is a need to rethink health approaches and envision a more inclusive view about care. Implying, perhaps, the intersectoral management with locoregional specificities and their inputs. Technologies or tools that consider users expectations along with the active involvement of families on care management and health services.

Memory bias is a potential limitation to be considered in cross-sectional studies, considering that many of the questions were based on past occurrences. So, it could be possible the experiments recall were evoked with more or less easiness by different participants. The effect of this potential information bias can not be estimated in this research.

FINAL CONSIDERATIONS

The family members who participated in the study were primarily women, aged 30 years or more, retired people with an income lower than one MG, which confirms the association of TB with poverty and unequal income distribution. In relation to the clinical-epidemiological aspects of the relative with TB, there was a substantial number of patients at home, and pulmonary TB was the predominant and transmissible clinical form.

Results also suggested weaknesses related to the families care management. Such relation can be observed when family members express doubts about the TB etiology or even when they signal protective behaviors that are not justified by the disease transmission cycle, such as deprivation of domestic utensils to the patient and curtailment of his transit in the residence. Yet, suffering and sadness are the expressions revealed in the coexistence with TB patients.

This study demonstrated a health practice not driven by the families, especially in the organization of DOT, and from this research, it is expected other studies emerge and show, with considerable evidence, the role of families in the control of TB.

It is also expected that families may become the centrality of the political project that was thought for the health, in order to have autonomy and solvability in the treatment related to their health necessities. For this, it is necessary that public policies support the families, not only in relation to clinical management and participation in the TB patient care, but also with regard to their participation in the management of health services.

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Received: March 11, 2011
Approved: March 7, 2012