

Delay in seeking initial care for Tuberculosis Diagnosis*

ATRASO NA PROCURA PELO PRIMEIRO ATENDIMENTO PARA O DIAGNÓSTICO DA TUBERCULOSE

DEMORA EN LA BÚSQUEDA DE LA PRIMERA CONSULTA PARA EL DIAGNÓSTICO DE LA TUBERCULOSIS

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ABSTRACT

Descriptive study, which aimed to analyze the time between the perception of TB symptoms onset and the first search for health services, according to TB patient characteristics in São José do Rio Preto - SP. 97 TB patients in treatment were interviewed with a structured instrument. The delay was identified by the median time between the perception of TB symptom's onset and the patients demand for care (> 15 days). To identify the variables related to delay the prevalence ratio were calculated. There was a delay seeking care among: male patients, aged 18 to 29 and 50 to 59 years, lower education and higher family income, pulmonary cases without HIV co-infection, presenting milder symptoms, users of alcoholic beverages and tobacco, those who did not perform preventive health control, and who sought health services closer to home. The recognition of users' profiles in the search for care is paramount for defining strategies that favor the use of services in a timely manner.

DESCRIPTORS

Tuberculosis
Delayed diagnosis
Health Services Accessibility
Patient acceptance of health care

RESUMO

Estudo descritivo que objetivou analisar o tempo decorrido entre a percepção dos sintomas da tuberculose (TB) e a primeira busca por serviço de saúde segundo características dos doentes com TB em São José do Rio Preto - SP. Entrevistaram-se 97 doentes com TB utilizando instrumento estruturado. Identificou-se atraso do doente pela mediana do tempo entre a percepção dos sintomas e busca por atendimento (> 15 dias). Calculou-se a razão de prevalência para identificar variáveis relacionadas ao atraso. Houve atraso entre: doentes do sexo masculino, com 18 a 29 e 50 a 59 anos, baixa escolaridade, maior renda familiar, casos pulmonares, não coinfectados com HIV, sintomas fracos, consumidores de bebidas alcoólicas e tabaco, que não realizavam controle preventivo de saúde e procuravam o serviço de saúde mais próximo do domicílio. O reconhecimento do perfil dos usuários na busca por atendimento é primordial para definir estratégias que favoreçam a utilização dos serviços em momento oportuno.

DESCRIPTORIOS

Tuberculose
Diagnóstico tardio
Acesso aos Serviços de Saúde
Aceitação pelo paciente de cuidados de saúde

RESUMEN

Estudio descriptivo objetivando analizar el tiempo transcurrido entre la percepción de los primeros síntomas de tuberculosis (TB) y la búsqueda de una primera consulta en servicios de salud, según características de los enfermos de TB en São José de Rio Preto-SP. Fueron entrevistados 97 enfermos de TB, utilizándose instrumento estructurado. Se identificó atraso del enfermo por la mediana de tiempo entre percepción de síntomas y búsqueda de atención (>15 días). Se calculó la razón prevalente para identificar variables relacionadas al atraso. Existió atraso entre: enfermos masculinos, con 18 a 29 y 50 a 59 años, baja escolarización, mayor renta familiar, casos pulmonares, no coinfectados con HIV, síntomas débiles, consumidores de alcohol y tabaco, sin control sanitario preventivo, buscando servicio de salud próximo al domicilio. El reconocimiento del perfil de pacientes buscando atención es primordial para definir estrategias que favorezcan la utilización de los servicios en el momento oportuno.

DESCRIPTORIOS

Tuberculosis
Diagnóstico tardío
Accesibilidad a los Servicios de Salud
Aceptación de la Atención de Salud

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INTRODUCTION

The control of tuberculosis (TB) provides, among its principal activities, the elimination of the infections source in the community as a fundamental aspect for decreasing morbidity and mortality and interrupting the chain of transmission of this disease⁽¹⁾. In the year 2009, the global TB incidence was 140 cases per 100,000 inhabitants, while in Brazil 71,700 new cases were reported, with an estimated incidence of 45 cases per 100,000 inhabitants, leading the country to occupy 19th place in the ranking of 22 countries with the highest incidence of TB, and the 13th highest number of bacilliferous cases⁽¹⁾.

Studies have shown that high rates of TB incidence and prevalence are the result not only of the conditions that enable vulnerability to the illness, but also the delay in making the disease diagnosis⁽²⁻⁵⁾. Therefore, early diagnosis appears as a challenge considering the difficulties related both to the organization of health services, as the precariousness of integration of priority actions and the utilization of fragmented practices that limit the access to services offered in health⁽⁶⁾, as well as sociocultural, economic and geographic aspects intrinsic to the TB patients that determine the search, the utilization and the acceptance of care provided. These issues are seen as possible obstacles to the effectiveness of programs and health services since the results of the health indicators are obtained from the moment that the services are accessible and the users accept, utilize and give continuity to this assistance⁽³⁾.

Once the importance of the contribution of the patients to TB diagnosis delay, international studies^(3,5) have been attempting to uncover the aspects that contribute to the delayed utilization of health services and that, therefore, are characterized as a barrier to obtaining timely diagnosis. Aspects related to the patient's knowledge about the disease, the distance between home and the health facility, costs related to transportation, inability to miss work and commitments, as well as satisfaction with the health care services provided, and the search for alternatives care are identified as determinants for access to diagnosis of the disease^(3,5). In Brazil, however, little is known about the behavioral aspects intrinsic to the TB patient and the aspects that influence the search for care and obtaining diagnostics, as well as the time spent in this process. Using the descriptors delayed diagnosis and tuberculosis, 79 studies were identified in a systematic search in the Virtual Health Library (VHL) without specifying the year of publication. Of these, however, only three were conducted in Brazil and only one of these analyzed the aspects related to the TB diagnosis delay in seeking health care after perception of the symptoms of disease^(2,7-8).

Due to the burden of TB as a public health problem and the importance of early diagnosis as one of the conditions for its control, this study aimed to analyze the time between the perception of TB symptom's onset and the first search

for health services according to sociodemographic, clinical, economic and behavioral TB patients characteristics.

METHOD

Epidemiological cross sectional study conducted in the city of São José do Rio Preto – SP – Brazil in 2009. In the mentioned year, the municipal TB care network was regionalized in five health districts. At the primary care level, the municipality had 13 Basic Health Units (BHU), 11 Family Health Units (FHU) and five Emergency Care Units (ECU). At the secondary level, there was a Regional Specialty Clinic (NGA-60) with the Tuberculosis Control Program (TCP) and the Outpatient Aids Clinic. There were six hospitals in the tertiary level.

The TB suspects entrance for diagnosis in the municipal health care could be at any point of care and, once diagnosed, patients and communicants were referred to primary care services for their case management. At this care level, the TB patient is followed by a minimum team of generalist professionals (physician, nurse and auxiliary / technical nurse) who worked with technical support offered by the specialized team of TCP. The monitoring of the TB cases that required more attention, such as patients with medicines intoxication, atypical mycobacteria and multi-drug resistance (MDR) was conducted directly by the specialist teams of the TCP and the outpatient AIDS clinic (coinfected).

It is worth highlighting the important role of nurses in the management of TB cases in the municipality, as the professional that assumes the care coordination with other health services and maintains the bond with the users, promoting their participation in their treatment.

The study population consisted of TB patients under treatment in the municipality during the period of November 2008 to November 2009. During this period, 135 patients registered in São Paulo State TB information system (TB-WEB) were in treatment; however, only 110 met the inclusion criteria of the study. Those excluded were: 12 patients younger than 18 years, three inmates, two psychiatric patients and eight with diagnostic change. Nine patients refused to participate in the research, and one was unable to respond. A total of 100 patients were interviewed, however the final study population consisted in 97 subjects: two of them could not inform the time involved between the perception of the TB symptoms onset and the search for the first consultation, and one did not inform the first health service sought.

Data were collected through primary sources (interviews) and secondary sources (medical records consults and the TB-Web information system) in the period of July to December of 2009. A structured data collection instrument was used for the interviews to retrieve the course of the patient from the moment he perceived the TB symp-

Studies have shown that high rates of TB incidence and prevalence are the result not only of the conditions that enable vulnerability to the illness, but also the delay in making the disease diagnosis.

toms onset until the search for the first health services consultation. Interviews occurred in patients' homes or in the health services where they were followed.

For data analysis, the time (days) between TB patients realized their symptoms and the search for a first health care was labeled as the variable *time of the patient*. It is emphasized that this information related to the patient's seeking care, based on their health status self-assessment, which does not mean that the symptoms started exactly when the patient took the initiative to search for health services.

Then, due to the fact that there was no consensual definition of the appropriate time for TB patients seeking care after realizing the symptoms of the disease⁽³⁾, in this

study, we defined *patient delay in seeking care* through one cutoff point for the variable *time of the patient*. This cutoff point was the median time and delay was defined as more than 15 days, forming two groups: with and without delay (dependent variables). We decided to use the median because the distribution of the values related to patients' responses to the variable *time* was asymmetrical, enabling the interference of outliers.

The prevalence ratio (PR) (Figure 1) was calculated to identify which categories of the selected independent variables were associated with patient delay in seeking care. The first category of each variable was standardized as the numerator. We constructed confidence intervals (95% CI), adopting a significance level of 5%.

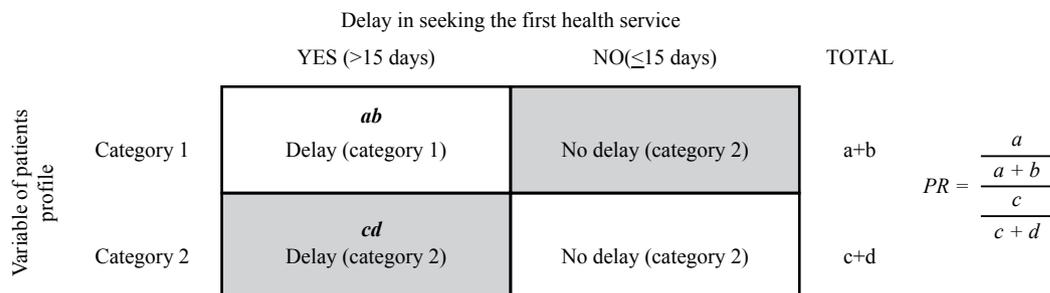


Figure 1 - Proposed schema for calculating the prevalence ratio, according to the delay in seeking the first health service and patient profile variables - São José do Rio Preto, 2009.

The variables chosen for analyzing *patient delay* were the following TB patients characteristics: sociodemographic and economic (gender, age range, marital status, education, household income, employment status), medical (clinical form of the disease, type of case, TB/HIV co-infection, perception about TB symptom intensity), and behavioral (tobacco and alcohol consumption, engaging in preventive actions (before TB), demand health services closer to home (before TB), first health service sought at the TB symptoms onset, knowledge about TB before diagnosis).

It is emphasized that information about the intensity of the TB symptoms and knowledge about TB before diagnosis were obtained from the patients' perception with

predetermined categories of responses (mild to strong symptoms, and poor to satisfactory knowledge); other benchmarking measures were not used.

The project was approved by the Ethics Committee of the Faculty of Medicine of São José do Rio Preto according to the protocol #7081/2008.

RESULTS

The median time between the perception of TB symptoms and the search for the first consultation in a health service was 15 days, with an interquartile interval of 4-45 days (Figure 2). In some cases the patients were observed to have exceeded 90 days.

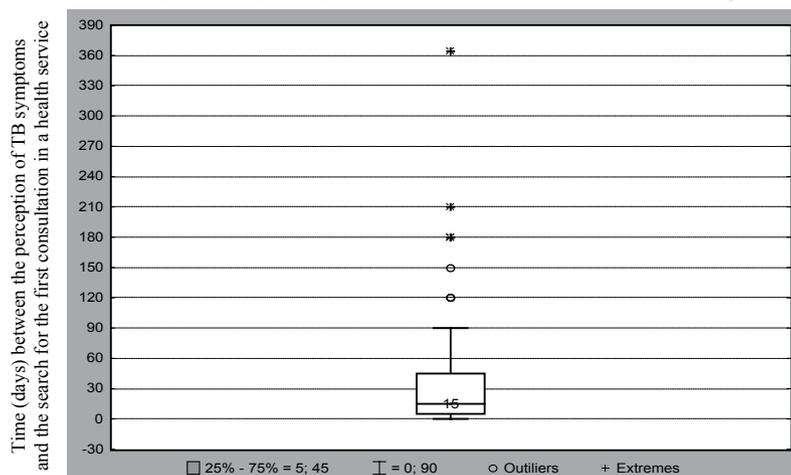


Figure 2 - Time (days) between the perception of TB symptoms and the search for the first consultation in a health service - São José do Rio Preto, 2009.

There was a predominance of males, who presented greater delay in searching for the first consultation. Eighteen-29 years old patients had a greater delay when compared to all age ranges, except for patients whose age was between 50 and 59 years old. Unmarried patients delayed to search their first consultation,

compared to those married and widowed and with lower education. A statistically significant difference was found between family income and delay in seeking care, and the TB patients who had family incomes greater than five minimum wages (MW) had a greater delay (Table 1).

Table 1 – Prevalence ratio of delay in seeking care according to sociodemographic and economic variables of TB patients – São José do Rio Preto, 2009

Sociodemographic and economic variables of TB patients		Delay	No Delay	TOTAL (N = 97)	RP*	CI
Gender	Female	15	21	36	0.91	[0.57;1.46]
	Male	28	33	61		
Age Range (in years)	18 - 29 ⁽¹⁾	9	8	17	RP _{1/2} - 1.47 RP _{1/3} - 1.47 RP _{1/4} - 0.88 RP _{1/5} - 1.13	[0.74;2.93] [0.74;2.93] [0.48;1.62] [0.56;2.29]
	30 - 39 ⁽²⁾	9	16	25		
	40 - 49 ⁽³⁾	9	16	25		
	50 - 59 ⁽⁴⁾	9	6	15		
	higher than 60 ⁽⁵⁾	7	8	15		
Civil Status	Single ⁽¹⁾	17	19	36	RP _{1/2} - 1.10 RP _{1/3} - 0.94 RP _{1/4} - 1.42	[0.67;1.80] [0.46;1.92] [0.53;3.80]
	Married ⁽²⁾	18	24	42		
	Divorced ⁽³⁾	5	5	10		
	Widowed ⁽⁴⁾	3	6	9		
Education	No education or incomplete primary education incomplete	32	37	69	1.18	[0.70;2.00]
	Completed primary education or higher	11	17	28		
Employment Situation	With remuneration	30	37	67	1.03	[0.63;1.68]
	Without remuneration	13	17	30		
Family Income (in MW)	Between 0 to 2 MW ⁽¹⁾	20	34	54	RP _{1/2} - 0.65 RP _{1/3} - 0.20	[0.41; 1.02] [0.14;0.28]
	Between 2 to 5 MW ⁽²⁾	20	15	35		
	More than 5 MW ⁽³⁾	3	5	8		

*RP1/n equates to prevalence ratio between category 1 in relation to category n, with n ranging from 2 to 5. MW – Minimum wage

Table 2 - Prevalence ratio of the delay in seeking care according to clinical variables in TB patients - São José do Rio Preto, 2009

Clinical variables of TB patients		Delay	No Delay	TOTAL (N=97)	RP*	CI
Clinical Form of TB	Pulmonary	36	43	79	1.17	[0.63;2.19]
	Extrapulmonary	7	11	18		
Type of Cases	New Case	39	51	90	0.76	[0.38;1.50]
	Recurrence / retreatment	4	3	7		
TB/HIV Coinfection	Yes	6	11	17	0.76	[0.38;1.51]
	No	37	43	80		
Perception about TB symptoms	Strong	30	41	71	0.85	[0.53;1.35]
	Weak	13	13	26		

*RP1/n equates to prevalence ratio between category 1 in relation to category n, with n ranging from 2 to 5.

Table 3 - Prevalence ratio of the delay in seeking care according to behavioral variables of TB patients - São José do Rio Preto, 2009

Behavioral variables of TB patients		Delay	No Delay	TOTAL (N = 97)	RP*	CI
Consumed alcoholic beverages	Yes	33	38	71	1,21	[0,70;2,09]
	No	10	16	26		
Tobacco Use	Yes	35	24	59	1,19	[0,81;1,74]
	No	19	19	38		
Involved in preventive actions before TB	Yes	30	41	71	0,85	[0,53;1,35]
	No	13	13	26		
Procured health services close to home	Yes	35	40	75	1,28	[0,70;2,35]
	No	8	14	22		
Knowledge about TB before the diagnosis	Satisfactory	14	16	30	1,08	[0,67;1,73]
	Precarious	29	38	67		
Initial health service procured when perceived TB symptoms	Basic care ⁽¹⁾	14	15	29	RP _{1/2} - 1,01 RP _{1/3} - 1,61	[0,62;1,63] [0,75;3,47]
	Urgent care ⁽²⁾	23	25	48		
	Specialist care ⁽³⁾	6	14	20		

*RP1/n equates to prevalence ratio between category 1 in relation to category n, with n ranging from 2 to 5.

Patients with pulmonary TB, classified as recurrent, not coinfecting with HIV and with weak symptoms had a greater delay in seeking health services (Table 2).

Those TB patients who reported consuming alcoholic beverages and tobacco, who did not participate in preventive health control, who sought health services closer to home before TB and who reported having adequate knowledge about TB delayed more in searching care, especially those who chose to seek the primary health services (Table 3).

DISCUSSION

The prevalence of TB in males in this study pointed to a greater male susceptibility to the disease and reflected the lifestyle habits and the ability of women to be more careful with their health than men. In this sense, it was verified that the presence of the men in the health services was predominantly linked to reason for the illness⁽⁹⁾, which reveals the roles assumed socially by men and women and the differences in expressing and perceiving the need to search for care. Although the male gender assumes greater role in the profile of TB morbidity and mortality, men delayed their search for health care services more than women. About this aspect, differences exist in the literature showing that the expression of gender is diverse within each country: the same result was obtained in India⁽⁵⁾; in Colombia, there was no difference in the time of seeking care between men and women⁽¹⁰⁾ but, in Tanzania⁽⁴⁾, by reasons related to cultural aspects incurred in the absence of autonomy and access to financial resources, women delayed to seek TB diagnosis. Another aspect to be considered referred to the predominance of delay among 18-29 years old patients, which revealed the tendency of these individuals support economically the family and also the influence of the health services opening hours in the pattern of seeking care behavior^(7,11). Moreover, data from the literature have reaffirmed the higher probability for individuals with advanced age to seek out more doctor visits due to the involvement of chronic and degenerative illnesses that need more monitoring⁽¹²⁾. However, in this study 50 to 59 years old patients took more time to seek care and it can be explained by the co-existence of other diseases that could have masked the TB symptoms, making complex the perception of the disease. Furthermore, TB symptoms are often attributed to other diseases related to the respiratory system, contributing to the worsening of the delay of the clinical diagnosis^(7,12-13).

In this study, the delay in seeking care may have been influenced by the predominance of patients with low educational levels, which is consistent with other findings that related grade levels to lack of knowledge and self-perceived health status, and the search for care linked to worsening of the clinical status^(4-5,14). The existence of a possible link between levels of education and income is also noteworthy, since there was a greater search for care

among individuals with lower income and more years of schooling⁽¹²⁾. Therefore, we do not discard the possibility of interaction between the characteristics of the profile of patients in the definition of time in searching for the first consultation.

In this study, the possibility that TB patients have undervalued the symptoms of the disease corroborated with the severity perceived of the symptoms for the demand for health services⁽¹³⁻¹⁵⁾. The fact that one of the first symptoms of pulmonary TB⁽⁵⁾ (cough) initially presented in a milder manner^(7,16) and be considered as a consequence of smoking⁽¹⁷⁾ could remove the suspicion of TB or other severe disease among patients, leading them to not feel the need to search care in a health facility. The delay in seeking care among TB patients who consumed alcohol concurs with other studies^(5,18) and may be related to poor perception about their health, as well as the lack of habit of seeking medical care.

The high frequency of alcoholism and smoking among TB patients and their influence on outbreaks and aggravation of the clinical disease⁽⁷⁾ raises the necessity of health professionals questioning users about these behavioral characteristics and being sensitized about other characteristics related to patient delay in seeking care shown by this study, favoring the suspicion of respiratory symptoms and decreasing the delay in obtaining the diagnosis and initiation of treatment among patients.

In São José do Rio Preto, the TB patients failure in search for routine or preventive care, as well as the proximity of health services, were not determinants in seeking treatment in less time among the TB patients, as also found in another study⁽⁶⁾, revealing that, after the perception of a problem / necessity, the search for care occurs due to the credibility attributed to health services and the bond with the professionals of certain health care services. Thus, the regular use of a service can reflect the existence of a *gateway* to the health system for each new need / problem⁽¹⁹⁾, regardless the geographical distance between patients' home and the health service.

In the same way, the fear of a new TB diagnosis, as well as a bad experience and possible dissatisfaction with previously received care may have led patients who were in relapse or retreatment to postpone seeking care. Therefore, evaluation of patient satisfaction regarding the care offered in the health services is paramount, since it reveals the way in which the user has received care. If the user is satisfied with his attendance, he returns to the service because it is a reference for the resolution of problems / needs, ensuring longitudinality of care in each new need for perceived health. In order to facilitate the access and the use of health services, intersectoral actions to improve the work organization and information flow between the different levels of care is very important. In addition, strategies shared among the various social actors that promote social participation are needed, directing the supply of care according to the community needs⁽²⁰⁾.

There was a quick search for health services among patients with HIV coinfection, probably because they possess a bond and already perform constant health checks in a reference service for people living with HIV/aids in the city. Furthermore, these individuals knew their immunosuppression status and manifested symptoms of TB more severely. Contrary to this result, the literature reveals greater delay in seeking a diagnosis among coinfecting patients⁽¹⁴⁾, which may be related to fear of being diagnosed with TB and the presence of signs and symptoms common to both diseases, such as weight loss, which can influence the perception of changes in their health.

TB patients who reported having adequate knowledge about the disease had a greater delay in seeking health services. For a better analysis of this relationship, we would need to use a more appropriate tool to measure knowledge of TB patients, encompassing aspects of symptomatology, transmission and consequences of late diagnosis and treatment.

With regard to the preference of most TB patients for Emergency Care Units, it is emphasized that, in Brazil, there is a policy to encourage the construction of new units, which contributes to the persistent use of these services. Difficult access, assumption of inability and lack of confidence in the resolution of the problem, and inexistence of vacancies for obtaining care in primary care services are possible causes that can induce the direct demand for the Emergency Care Units, corroborating with the delay found among patients who sought primary services within this study. Such behavior is not conducive to organization of the demand and the care of chronic conditions such as TB, since Emergency Care units do not have a role in care coordination^(7,13,21-22).

In this sense, independent of the type of health care searched, the initiative to seek assistance is shown to be strongly linked to the bond, the satisfaction with care provided, and the confidence in the experience and the capacity of the health team members⁽¹⁹⁻²⁰⁾. Seeking care can occur in more or less time due to geographical, political, economic, social and anthropological reasons from the context of the individual^(7,12,15).

Among the limitations of this study, there was patient recall bias about the onset and identification of the symptoms of TB. It is noteworthy that the interviews were made possible through a partnership with the services and support of local health teams in locating patients and scheduling the interviews.

CONCLUSION

The late searching behavior for care can be considered serious from an epidemiological point of view since it provides a greater dissemination and worsening of the disease.

In this sense, this study contributes to the identification of a profile of users who delayed seeking care, subsidizing health teams to recognize this and to define strategies that emphasize the demystification of TB in the community, early self-perception of disease symptoms, reducing barriers of access to care, and strengthening the bond with health care workers in order to favor the search for care among patients in less time, making a timely diagnosis.

It is important to highlight that some of the patients characteristics that delayed in seeking care transcend the health sector, making intersectoral operations imperative for TB control.

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