

## Health care seeking behavior and patient delay in tuberculosis diagnosis

Comportamento de busca por cuidados em saúde e atraso do paciente no diagnóstico da tuberculose

Comportamiento de búsqueda de atención de salud y retraso del paciente en el diagnóstico de la tuberculosis

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### Abstract

*Delays in diagnosis of TB cases are major impeding factors in the control of TB. The objectives of this study were to describe the health care seeking behavior of TB patients, assessing patient delay and the number of health care facilities visited before the start of TB treatment. A cross-sectional study was carried out with adult patients with pulmonary TB presenting to two TB facilities to start treatment. We found a median patient delay of 20 days. The factors associated negatively with patient delay in multivariate analysis were weight loss, and have sought treatment because of the first symptom. We also demonstrated that 44.8% of patients incorrectly reported the mode of transmission of TB. In addition, the local of first attendance was an emergency room of public hospitals in 37.3% of patients. We demonstrated that the median patient delay in TB diagnosis in two TB services in a region with a high prevalence of TB was 20 days, and the protective factors associated with this delay in multivariate analysis were weight loss, and have sought treatment because of the first symptom.*

*Tuberculosis; Delayed Diagnosis; Time-to-Treatment*

### Resumo

*Atrasos no diagnóstico de casos de tuberculose são os principais fatores que impedem o controle da doença. Os objetivos deste estudo foram descrever a trajetória de pacientes com tuberculose, avaliando a demora do paciente e o número de unidades de saúde visitadas antes do início do tratamento. Estudo transversal foi conduzido com pacientes com idade  $\geq 18$  anos e com diagnóstico de tuberculose pulmonar, que responderam a um questionário. A média de idade dos pacientes foi de  $40,4 \pm 16,1$ . Foi encontrada uma mediana de 20 dias no atraso dos pacientes. Também foi verificado que 44,8% relataram incorretamente o modo de transmissão da tuberculose. Além disso, o local do primeiro atendimento para 37,3% dos pacientes foi uma emergência de hospital público. Encontrou-se uma mediana de 20 dias no atraso dos pacientes até o diagnóstico da tuberculose; os fatores protetores associados a este atraso na análise multivariada foram perda de peso e ter procurado tratamento por causa do primeiro sintoma.*

*Tuberculose; Diagnóstico Tardio; Tempo para o Tratamento*

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## Introduction

Tuberculosis (TB) is a major public health issue worldwide, particularly in low- and middle-income countries<sup>1</sup>. Delays in diagnosis and treatment of TB cases are major impeding factors in the control of TB. A single infectious person who remains untreated can infect between ten and fifteen people every year, spreading the infection in the community<sup>1,2</sup>. In addition, delayed TB diagnosis and treatment may result in more extensive disease and more complications, and increases the risk of mortality<sup>3,4,5</sup>.

The total delay in TB diagnosis can be divided into the length of patient delay and the length of health care system delay<sup>6</sup>. Socio-economic status, perceived severity of illness and symptom recognition, distance and physical access, and perceived quality and cost of health service provision are all factors associated with patient delay<sup>7</sup>.

Previous studies have shown that a delay in diagnosis is closely related to poor access to health care<sup>8,9</sup>. Despite TB control programs' recommendation that diagnosis should be made at the primary health care level, most patients are still diagnosed in hospitals. In fact, in Porto Alegre, Rio Grande do Sul State, Southern Brazil, 38.98% of TB cases were reported by hospitals<sup>10</sup>. Understanding the factors related to delay in diagnosis of disease is essential to reduce the period of transmission and the risk of exposure of other community members.

The objectives of this study were to describe the health care seeking behavior of TB patients, assessing patient delay and the number of health care facilities visited before the start of TB treatment.

## Materials and methods

We conducted a cross-sectional study in two TB services, located in the city of Porto Alegre, between February and December 2012. Porto Alegre is the city with the highest incidence of TB in Brazil (115 cases/100,000 population), with a cure rate of 67%. Also, the TB-HIV co-infection rate is the highest in the country (35%)<sup>11</sup>.

All adult patients ( $\geq 18$  years old) with pulmonary TB presenting to the two facilities that admit TB patients to start treatment were invited to participate. Pulmonary TB was diagnosed according to any of the following criteria established in the Brazilian Guidelines for Tuberculosis<sup>12</sup>. Patients who refused signing the consent form were excluded from the study.

Face-to-face interviews were performed using a standardized and pre-tested questionnaire

developed exclusively for this study to collect information on each patient at the time of admission. The interviews were conducted by the same interviewer, previously trained. Medical records were also reviewed. The following data were recorded: demographic data, symptoms before seeking health care, health care seeking behavior, type and number of health care facilities visited, and knowledge about TB.

Health care seeking time was defined as the duration (in days) between the onset of symptoms to the first visit to a health care facility (including hospital, TB services, primary health care clinics, etc). In order to evaluate the associated factors with patient delay, the study population was divided into two groups, according to the median time of health care seeking: group 1 ( $\geq$  median) and group 2 ( $<$  median). Individuals included in group 1 were considered to have "patient delay".

Data analysis was performed using SPSS 18.0 (IBM Corp., Armonk, United States). Data were presented as number of cases, mean  $\pm$  standard deviation (SD), or median with interquartile range (IQR). Categorical comparisons were performed by chi-square test using Yates's correction if indicated or by Fisher's exact test. Continuous variables were compared using the *t*-test or Wilcoxon test. Multivariate logistic regression analysis was used to evaluate risk factors for patient delay, using selection of factors associated ( $p \leq 0.20$ ) with delay in univariate analysis or those known to have clinical significance. Stepwise regression models were also examined to evaluate the possible collinearity among the predictors. The predictors selected in the final model were based on both statistical and clinical significance. The goodness of fit of the multiple logistic regression models was assessed using the Hosmer-Lemeshow test. Odds ratios (ORs) and nominal 95% confidence intervals (95% CIs) were presented. A two-sided  $p$ -value  $< 0.05$  was considered significant for all analyses.

On the basis of data from van der Werf et al.<sup>13</sup>, who informed that individuals reporting unemployment, cough or loss of weight before seeking health care had a longer patient delay, we estimated a sample size of 134 patients, under the assumptions of a type I error (two-sided) of 5% and a type II error of 10%.

## Results

One hundred thirty-nine patients met the inclusion criteria. Five patients refused to participate, then one hundred thirty-four patients were included in the analysis. The mean age of all pa-

tients was  $40.4 \pm 16.1$  years, 62.7% were males, and 59% were white. The majority of patients were literate and unemployed. Twenty-three patients (17.1%) were HIV positive. The characteristics of participants are summarized in Table 1.

Health seeking behavior, knowledge and perspectives of TB patients were described in Table 2. One hundred and seven patients (79.9%) sought treatment after the first symptom of TB. Among those who did not seek treatment soon after the onset of the first symptom, 44.8% did not because they thought the symptom was normal, 21.6% thought would improve without treatment, and 7.5% said that they could not miss work to sought treatment. One hundred and two patients (76.1%) sought care elsewhere before TB health center. The type of facility first sought by patients was: emergency of a public health hospital (n = 50, 49.1%), public health center (n = 35, 34.3%), private practice (n = 11, 10.8%), and emergency of a private hospital (n = 6, 5.9%). Overall, the median number of visits to health

care facilities before the diagnosis was 3 (IQR: 2-4). Thirty seven patients (27.6%) were diagnosed and started treatment at hospitals, and did not seek treatment at health centers. The reasons for not seeking treatment in health centers were: "it is difficult to get medical care there" (n = 15), "I thought my problem would not be solved there" (n = 12), "I don't know where is the health center I should go" (n = 7), and "I did not know I could seek a health center for this problem" (n = 3).

The median health care seeking time was 20 days (IQR: 7-46.3 days). According to this median time, 71 (52.9%) patients were included in group 1 ( $\geq 20$  days), and 63 (47%) in group 2 ( $< 20$  days). Table 3 summarizes the results of the univariate analysis. By univariate analysis, characteristics associated negatively with delayed initial health seeking were weight loss, sought care after the first symptom, and smear positive sputum.

Logistic regression analysis estimating the ORs of risk of patient delay was conducted. Age, sex, monthly household income  $< 1$  stan-

Table 1

Characteristics of study population (n = 134).

Characteristics	n (%), mean $\pm$ SD or median (IQR)
Age (years)	40.4 $\pm$ 16.1
Male sex	84 (62.7)
White race	79 (59.0)
Marital status	
Single	76 (56.7)
Married	39 (29.1)
Divorced/Separeted	10 (7.5)
Widowed	9 (6.7)
< 8 years of schooling	60 (44.8)
Literate	127 (94.8)
Employed	60 (44.8)
Living alone	26 (19.4)
Has a religion	99 (73.9)
Monthly household income $< 1$ standard minimum wage *	35 (26.1)
Institutionalization	39 (29.1)
Smoking habit	
Never smokers	41 (30.6)
Current smokers	45 (33.6)
Former smokers	48 (35.8)
Alcoholism	13 (9.7)
Drug use	14 (10.4)
HIV positive	23 (17.1)

IQR: interquartile range; SD: standard deviation.

\* 1 standard minimum wage corresponds to approximately US\$ 311.

Table 2

Health seeking behavior, knowledge and perspectives of TB patients (n = 134).

	n (%), mean $\pm$ SD or median (IQR)
Feels sick	96 (71.6)
Symptoms of disease	
Cough	57 (65.5)
Fever	59 (53.6)
Fatigue	18 (13.4)
Night sweats	73 (69.5)
Dyspnea	61 (54.0)
Weight loss	89 (80.2)
Sought treatment because of first symptom	107 (79.9)
Time to first health seeking, days	20.0 (7.0-46.3)
Why not sought treatment before?	
Thought the symptoms were normal	60 (44.8)
Thought would improve without treatment	29 (21.6)
Could not miss work to sought treatment	10 (7.5)
Someone suggested that you seek care	89 (66.4)
Sought care elsewhere before TB health center	102 (76.1)
Where?	
Public health center	35 (26.1)
Emergency of a public hospital	50 (37.3)
Emergency of a private hospital	6 (4.5)
Private practice	11 (8.2)
Number of facilities sought before diagnosis	3 (2-4)
Chest x-ray was requested somewhere	77 (57.5)
Sputum smear was requested somewhere	49 (36.6)
Medication was prescribed somewhere	49 (36.6)
Previous TB	35 (26.1)
Smear positive sputum	102 (76.1)
Correctly reported air as the main mode of transmission of TB	74 (55.2)
Perceived TB as being curable	128 (95.5)
Afraid of how other people will react when they know you have TB	52 (38.8)
Afraid that your friends and/or family members to move away from you if they know you have TB	31 (23.1)
Feel alone after discovering that you have TB	27 (20.1)
Concerned to keep away from others to avoid spreading TB	92 (68.7)
Afraid or ashamed to appear in the TB health center because other people can see that you are going there because you have TB	11 (8.2)
Feels guilty for your family to have to be taking care of you	24 (17.9)
Afraid to tell others that you have TB because they may find that you also have HIV/AIDS	38 (28.4)
Fear of having HIV/AIDS	71 (53.0)
Feels guilty for having TB due to some of your habits (smoking or use of alcohol beverages or other drug use)	54 (40.3)

IQR: interquartile range; SD: standard deviation.

ard minimum wage, weight loss, night sweats, fever, sought treatment after the first symptom, and previous TB were included in the multivari-

ate analysis. The variables associated with patient delay in multivariate logistic regression are shown in Table 4.

Table 3

Univariate analysis of factors associated with patient delay.

	Group 2 Patient delay < 20 days (n = 63)	Group 1 Patient delay ≥ 20 days (n = 71)	p-value
Age (years)	38.1 ± 14.1	42.4 ± 17.5	0.125
Male sex	39 (61.9)	45 (63.4)	0.999
White race	36 (57.1)	43 (60.6)	0.727
< 8 years of schooling	26 (41.3)	34 (47.9)	0.489
Literate	60 (95.2)	67 (94.4)	0.999
Employed	30 (49.2)	29 (40.8)	0.595
Living alone	11 (17.5)	15 (21.1)	0.665
Has a religion	44 (69.8)	55 (77.5)	0.332
Monthly household income < 1 standard minimum wage *	20 (31.7)	15 (21.1)	0.174
Institutionalization	20 (31.7)	19 (26.8)	0.571
Smoking habit			
Never smokers	19 (30.2)	22 (31.0)	0.999
Current smokers	20 (31.7)	25 (35.2)	0.716
Former smokers	24 (38.1)	24 (33.8)	0.718
Alcoholism	7 (11.1)	6 (8.5)	0.771
Drug use	7 (11.1)	7 (9.9)	0.999
HIV positive	13 (24.1)	10 (16.9)	0.362
Feels sick	44 (69.8)	52 (73.2)	0.704
Symptoms of disease			
Cough	31 (72.1)	26 (59.1)	0.261
Fever	31 (60.8)	28 (47.5)	0.183
Fatigue	8 (12.7)	10 (14.1)	0.999
Night sweats	39 (78.0)	34 (61.8)	0.091
Dyspnea	29 (54.7)	32 (53.3)	0.999
Weight loss	47 (88.7)	42 (72.4)	0.035
Sought treatment because of first symptom	57 (90.5)	50 (70.4)	0.005
Number of facilities sought before diagnosis	3 (2-4)	3 (1-3)	0.252
Smear positive sputum	53 (84.1)	49 (69.0)	0.045
Previous TB	12 (19.0)	23 (32.4)	0.114
Correctly reported air as the main mode of transmission of TB	37 (58.7)	37 (52.1)	0.489
Perceived TB as being curable	59 (93.7)	69 (97.2)	0.570
Afraid of how other people will react when they know you have TB	22 (34.9)	30 (42.3)	0.478
Afraid that your friends and/or family members to move away from you if they know you have TB	17 (27.0)	14 (19.7)	0.412
Feel alone after discovering that you have TB	10 (15.9)	17 (23.9)	0.285
Concerned to keep away from others to avoid spreading TB	45 (71.4)	47 (66.2)	0.578
Afraid or ashamed to appear in the TB health center because other people can see that you are going there because you have TB	5 (7.9)	6 (8.5)	0.999
Feels guilty for your family to have to be taking care of you	13 (20.6)	11 (15.5)	0.502
Afraid to tell others that you have TB because they may find that you also have HIV/AIDS	21 (33.3)	17 (23.9)	0.254
Fear of having HIV/AIDS	31 (49.2)	40 (56.3)	0.488
Feels guilty for having TB due to some of your habits (smoking or use of alcohol beverages or other drug use)	22 (34.9)	32 (45.1)	0.290

IQR: interquartile range; SD: standard deviation.

Note: Continuous variables (age) are presented as mean ± SD; other data are presented as n/N (%): number of cases with characteristic/total number of cases (percentage in the group), or median (interquartile range).

\* 1 standard minimum wage corresponds to approximately US\$ 311.

Table 4

Multivariate analysis of factors associated with patient delay.

Variables	p-value	OR	95%CI
Sought treatment because of first symptom	0.009	0.203	0.062-0.666
Weight loss	0.031	0.314	0.109-0.900
Constant	0.001	10.745	-

95%CI: 95% confidence interval; OR: odds ratio.

## Discussion

In this study, we found a median health care seeking time of 20 days. The protective factors for patient delay in multivariate analysis were weight loss, and have sought treatment because of the first symptom. We also demonstrated that approximately 50% of patients incorrectly reported the mode of transmission of TB. In addition, the local of first attendance was an emergency room of public hospitals in almost 40% of patients.

Identifying the sources of delay is a critical issue for an effective TB control. Patient delay may explain why many patients present with advanced disease and why a relatively high percentage of TB patients die. Furthermore, patient delays lead to increased spread of TB within the community<sup>14,15,16</sup>. There is no agreed definition of what constitutes an “acceptable” delay, and it probably depends on the local health services and the local epidemiological situation, with a shorter delay to be expected when incidence is high<sup>17</sup>. Care seeking or patient delay is widely variable in literature, ranging from 4.9 to 162 days<sup>18</sup>. In our study, patient delay was similar to that found by other authors in India<sup>19,20</sup>, Japan<sup>21</sup>, Hong Kong<sup>22</sup>, and Spain<sup>23</sup>.

Persons with suspected TB symptoms but who do not seek health care should be identified, and reasons for not seeking treatment need to be investigated. Having sought help after the appearance of the first symptom was a protective factor for patient delay in our study. The main reasons for delay among those who presented late to the health system involve financial, psychosocial and cultural characteristics of patients<sup>24,25</sup>.

We identified among those who did not seek treatment soon after the onset of the first symptom, that the main justifications were because they thought the symptom was normal, they thought would improve without treatment, and that they could not miss work to sought treatment. Similar reasons were described in another

study: patients “thought symptoms would go away” and “symptoms not considered serious”<sup>13</sup>. It has also been reported that patients awaiting symptoms resolution without specific treatment and can assign them to viral infections<sup>26,27,28,29,30</sup>.

Our results showed that weight loss was a protective factor for patient delay. In a recent study<sup>31</sup>, authors demonstrated that the presence of non-specific symptom of cough was a risk factor associated with longer delays, but if other pulmonary symptoms like loss of weight, for example, were considered together these delays could be shortened. Another previous study revealed that persistent cough not accompanied by symptoms such as weight loss and weakness could delay patients’ first initiative to seek help<sup>32</sup>. It is possible that patients’ knowledge that weight loss is one of the TB symptoms raised awareness of TB among them. However, the patients in our study demonstrate a lack of knowledge about TB, once almost one half did not know how the disease was transmitted. Misconceptions about TB transmission have been reported in other studies<sup>33</sup>, and it is related to delays in diagnosis and treatment non-adherence<sup>33,34,35,36</sup>. We could not show an association between patient delay and lack of knowledge about TB, but is important to develop strategies to improve patient education about their illness in the TB services, since it can have implications in treatment adherence. In the same way, it is important to train health professionals in identifying these patients. One study<sup>37</sup> conducted in Vitória, Espírito Santo State, Brazil, found that the majority of respiratory symptomatic patients (71%) had not sought health care facility because of cough, the symptom most commonly associated with TB.

The median number of visits to health care facilities before the diagnosis was 3, and the number of sputum smears requested in those facilities was very low (less than 40%). Loureiro et al.<sup>38</sup> also demonstrated that sputum smears were requested in 42.1% of patients who sought care in primary care level. This finding could be

related to lack of awareness of TB among health care workers<sup>39</sup>. Another concerning finding of the present study was that the local of first attendance was an emergency room of public hospitals in almost 40% of patients. In addition, almost 30% were diagnosed and started treatment at hospitals, and did not seek treatment at health centers. The reasons for not seeking treatment in health centers were mainly poor access to medical care in such places, and lack of credibility in the treatment that can be offered there. In addition, lack of resoluteness of patient's symptoms in the primary care level is an issue to be considered. Another fact to be considered is the greater flexibility of office hours in hospitals as compared with health centers<sup>40</sup>. One study recently reported that most patients treated for TB in a primary health clinic in a high TB incidence city in Southeast Brazil, initially sought medical attention at an emergency room rather than the primary health care clinic, as recommended by the public health system in Brazil<sup>41</sup>. In another study conducted in Vitória, Brazil, 30.7% of patients initially seek treatment at an emergency room<sup>38</sup>. Emergency room is one of the main entrances for public health care system in Brazil, where a significant number of individuals with respiratory symptoms like cough go in order to get the first aid. Considering that emergency room is a site with a high potential for propagation of TB, efforts should be made for early diagnosis and treatment. Furthermore, the reasons for patients seeking emergencies instead of health centers should be better investigated.

Some considerations should be taken into account when interpreting the results of this study. First, patient delays were determined retrospectively then they could have been limited by recall bias. Nevertheless, our findings indicate that there is a significant time elapsed before patients sought medical care. Second, we evaluated only patient delay, and not health care system delay, that could have a role in delay. Although delayed initial health seeking covers only a part of the total delay, it can impact on transmission. A study

conducted in Foz do Iguaçu, Paraná State, Brazil showed that the time between first consultation and diagnosis was not the main problem in total time delayed, and patient delay was more important<sup>42</sup>. Additionally, the difficulty of establishing the boundaries between the patient delay and the health system delay was previously discussed, since previous experiences may influence patient's decision to seek the service again or delay the search for care<sup>42</sup>. Also, we chose a cutoff of 20 days (median health care seeking time) that is near the time reported in the media for seeking care (cough  $\geq 2$  weeks); if we had chosen another cutoff, we might have found other associations. However, a similar cutoff was already used in a study in Brazil<sup>43</sup>. In addition, the use of a previously validated questionnaire<sup>44</sup> would facilitate comparison with data from other studies. Nevertheless, the use of a specific questionnaire was useful for characterizing these patients, identifying regional differences in health assistance and factors associated with delayed diagnosis in this population. Eventually this knowledge will be helpful to adequate planning of future actions in the area studied. Finally, we did not evaluate the impact that patient delay may have on mortality. In spite of these concerns, we recruited patients from two TB services, and we expect the results may thus be applied to other similar settings.

In conclusion, we demonstrated that the median health care seeking time in two TB services in a region with a high prevalence of TB was 20 days, and the factors associated with patient delay in multivariate analysis were weight loss, and have sought treatment because of the first symptom. Also, patients studied showed a lack of knowledge of TB, and a high percentage of them first sought attendance in emergency rooms of public hospitals. Future studies on reasons for not seeking care in health centers or TB services may be warranted in this setting. In addition, our results showed that there is a need for public health interventions, focusing on TB education programs, including awareness of early symptoms of disease.

## Resumen

*Los retrasos en el diagnóstico de la tuberculosis son los principales factores que impiden el control de la tuberculosis. Entre los objetivos de este estudio se encuentra la descripción de la trayectoria de los pacientes con tuberculosis, evaluando el retraso en el diagnóstico del paciente y el número de establecimientos de salud visitados antes de iniciar el tratamiento para la tuberculosis. Se realizó un estudio transversal con pacientes  $\geq 18$  años de edad y con diagnóstico de tuberculosis pulmonar que respondieron a un cuestionario. La edad media de los pacientes fue de  $40,4 \pm 16,1$ . Se encontró un media de 20 días en el retraso del diagnóstico a los pacientes. También se halló que un 44,8 % informó incorrectamente del modo de transmisión de la tuberculosis. Por otra parte, el primer punto de asistencia para un 37,3 % de los pacientes fue el servicio de urgencias en un hospital público. Se halló un promedio de 20 días en el retraso del diagnóstico de la tuberculosis a los pacientes, los factores protectores asociados con el retraso en el análisis multivariado fueron la pérdida de peso y conseguir el tratamiento debido cuando se presenta el primer síntoma.*

*Tuberculosis; Diagnóstico Tardío; Tiempo de Tratamiento*

## Contributors

C. P. B. Almeida designed the study, collected data, and help to draft the manuscript. E. K. Skupien collected and analyzed data, and help to draft the manuscript. D. R. Silva designed the study, analyzed data, and wrote the paper.

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## Conflicts of interest

The authors have no conflicts of interest to disclose.

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