Original article

Sociodemographic, clinical and epidemiological aspects of Tuberculosis treatment abandonment in Pernambuco, Brazil, 2001-2014

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Abstract

Objective: to describe abandonment rates according to sociodemographic, clinical and epidemiological characteristics of new tuberculosis cases being treated in Pernambuco State, Brazil. **Methods**: this is a descriptive ecological study using data from the Information System for Notifiable Diseases from 2001 to 2014; the abandonment rate was calculated by the Regional Administration on Health (GERES). **Results**: of the 57,015 new cases, 6,474 (11.3%) abandoned treatment, although abandonment decreased from 16.4% (2001) to 9.3% (2014); the abandonment rate in GERES I Recife, III Palmares, IV Caruaru, VIII Petrolina and IX Ouricuri was still >5% in 2014; the rate was higher in males (11.9%), people aged 20-39 (12.7%), people with incomplete elementary school (12.1%), black-skinned people (13.7%), institutionalized people (12.5%) and those with pulmonary + extrapulmonary tuberculosis (14.1%). **Conclusion**: despite the decrease, the abandonment rate remained high; males, adults with low education level, black-skinned people, institutionalized patients and patients with pulmonary + extrapulmonary tuberculosis seemed more prone to abandoning treatment.

Keywords: Tuberculosis; Treatment Refusal; Medication Adherence; Epidemiology, Descriptive.

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Introduction

Tuberculosis is an infectious disease with expressive global magnitude. It is estimated that, in 2013, there were nine million new cases and one million tuberculosis-related deaths.[1] Furthermore, a third of the world's population is believed to be infected with its etiological agent, *Mycobacterium tuberculosis*, popularly known as Koch bacillus.[1,2]

In Brazil, more than one million new cases were confirmed from 2001 to 2014; of these cases, about 70,000 evolved to death.[3] The treatment is available all over the country, provided exclusively by the Brazilian National Health System (SUS), in order to control the illness in the population to achieve the cure target of over 85% and treatment abandonment of less than 5%.[4] Considering the need for a close relationship with the population and the territory, Primary Health Care is the main gateway for tuberculosis care.[5] Such proximity is essential, since the treatment lasts a long time – at least six months –, and is divided into attack and maintenance phases.[5]

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One of the most relevant adverse variables is the abandonment of the treatment itself, understood by the Brazilian Ministry of Health as the patient being absent for more than 30 consecutive days after the return date.[4] This non-adherence generates an impact on the incidence indicators, multidrug resistance, associated diseases and conditions, and mortality.[5] On a national level, among the Brazilian federative units, the abandonment rates ranged from 2.8 to 15.9% in 2014.[3] The associated causes for treatment abandonment involve factors intrinsic to the users (use of alcohol and other drugs, false impression of cure and discomfort caused by the lack of food) and extrinsic factors (type of treatment and operationalization of health services).[6]

Considering the persistence of tuberculosis, the difficulty in maintaining adherence to treatment and the risks of abandoning the treatment, the analysis of spatial compatibility and of the territorial profile of this universe is essential. Above all, in order to align and implement strategic public policies and control measures consistent with the real situation.

This study aimed to describe abandonment rates according to sociodemographic, clinical and epidemiological characteristics of new tuberculosis cases in treatment in Pernambuco State, Brazil, from 2001 to 2014.

Methods

This is a descriptive ecological study with data from the Information System for Notifiable Diseases (Sinan), available on the website of the IT Department of the Brazilian National Health System (Datasus) and updated on May 25th, 2016.[7]

Pernambuco, located in the Northeast region of Brazil, is formed by 184 municipalities, in addition to the district of Fernando de Noronha island. According to state health policies, 12 units of Regional Administration on Health (GERES) were created. These units are composed by neighboring municipalities, in order to ensure that SUS works properly, and are organized as follows: I Recife; II Limoeiro; III Palmares; IV Caruaru; V Garanhuns; VI Arcoverde; VII Salgueiro; VIII Petrolina; IX Ouricuri; X Afogados da Ingazeira; XI Serra Talhada; and XII Goiana.

The study population consisted of all individuals registered in the system as a new case, which were closed due to abandonment, reported by the 12 GERES from January 1st, 2001 to December 31st, 2014. Cases with the following outcomes were excluded: ignored/blank, cured, death by tuberculosis, death by other causes, referral, change in diagnosis and drug-resistant tuberculosis. Cases registered in 2015 and 2016, subject to several types of changes were not considered, in order to prevent changes in the results.

The abandonment rate of tuberculosis treatment was calculated according to the notifying GERES (I, II, III, IV, V, VI, VII, VIII, IX, X, XI and XII), by dividing the number of abandonments by the total number of new cases of all forms of the disease, in each analyzed unit, multiplied by 100.[4]

The following variables were considered to characterize the cases:

a) Sociodemographic

- sex (male, female);
- age (in years: 0 to 9; 10 to 19; 20 to 39; 40 to 59; 60 to 79; 80 or over);

- education level (illiterate, incomplete middle school, complete middle school, incomplete high school, complete high school, incomplete higher education, complete higher education);
- ethnicity/skin color (white, black, brown, Asian, indigenous);
- institutionalization (prison, nursing home, orphanage, psychiatric hospital, others); and
- special population (deprivation of liberty; homelessness; health professional; recipient of cash transfer programs, immigrant).

b) Clinical and epidemiological

- clinical form (pulmonary, extrapulmonary, pulmonary + extrapulmonary);
- clinical form of extrapulmonary (pleural, peripheral lymph node, genitourinary, bone, ocular, miliary; meningoencephalitis; cutaneous; laryngeal; other); and
- associated diseases and disorders (acquired immunodeficiency syndrome [AIDS]; alcohol consumption, illicit drugs, smoking, diabetes, mental illness, others).

For the descriptive statistical analysis and distribution of absolute and relative frequency, we used the dynamic resources provided by Microsoft Excel 2010 and Epi Info version 7.1.4. For the construction of maps of abandonment rates according to notifying GERES, we used ArcGIS software 10.4.1. According to the recommendations of the National Health Council (CNS), Resolution No. 510, dated April 7th 2016,[8] the study was not submitted to a Research Ethics Committee because it used a secondary database and of public domain.

Results

From 2001 to 2014, there were 57,015 new cases of all forms of tuberculosis in the state of Pernambuco; 6,473 of these cases were classified as treatment 'abandonment', which is equivalent to an abandonment rate of 11.3%. During the study period, there was a reduction in this rate, from 16.4% (2001) to 9.3% (2014), although the lowest value (8.3%) has been observed in 2006 (Figure 1).

Figure 2 illustrates the distribution of the treatment abandonment rates in each GERES. In 2001, only three GERES – II Limoeiro, IX Ouricuri and X Afogados da Ingazeira – presented <5% abandonment, whilst two – VII Salgueiro and XI Serra Talhada – had rates that ranged from 5 to 15%, and seven – I Recife, III Palmares, IV Caruru, V Garanhuns, VI Arcoverde, VIII Petrolina and XII Goiana – registered rates from 15 to 26%, far above the recommended. In 2014, most GERES reported <5% abandonment rates – except I Recife, III Palmares IV Caruaru, VIII and IX Ouricuri, where the rates varied from 5 to 15%. The only regional that presented worse indicators was IX Ouricuri.

When we stratified the abandonment rate of tuberculosis treatment according to sociodemographic factors, we noticed

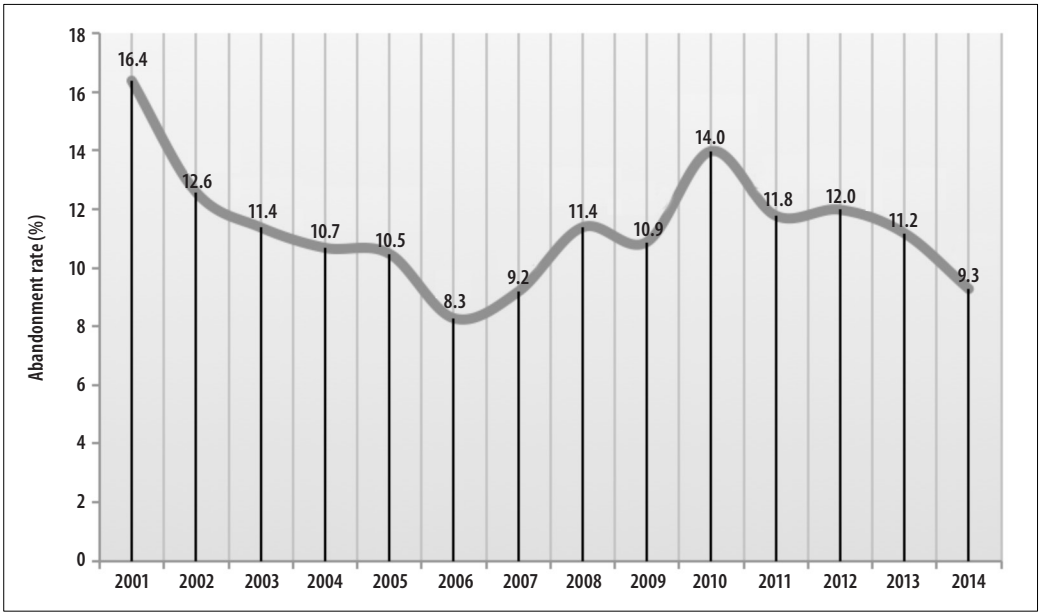

Figure 1 – Abandonment rates (%) of tuberculosis treatment in the state of Pernambuco, Brazil, 2001-2014

that the indicator was higher among males (11.9%), people aged 20-39 years (12.7%), with incomplete elementary education (12.1%) and with black skin color (13.3%), followed by indigenous people (13.2%), individuals institutionalized in psychiatric hospitals (12.6%), and those in orphanages (12.5%) (Table 1).

We could not characterize the abandonment rate in special populations, given that 93 to 99.4% of the records of the variables related to them were ignored or not filled/blank (Table 2).

The distribution of the abandonment rates according to clinical and epidemiological characteristics are shown in Table 3. Abandonment was more frequent among individuals with pulmonary tuberculosis associated with extrapulmonary tuberculosis (14.1%). Among the rates of the extrapulmonary form, we found that 84.2% of the data were ignored or blank, with regard to the specific location affected by the disease. Users of alcohol were the ones who abandoned treatment the most (15.4%), whilst more than 50% of the records of other variables related to associated diseases and disorders were ignored or blank.

Discussion

It is evident that abandonment cases have become less frequent in the state of Pernambuco, in different proportions between the GERES. However, its indicator remains high. We could notice higher frequency of treatment abandonment among males, young adults with low education level, black-skinned, those institutionalized in psychiatric hospitals, patients with pulmonary tuberculosis associated with extrapulmonary tuberculosis and alcohol users.

The proportional decrease of abandonment rates in Pernambuco complies with the one observed in Brazil as a whole, according to a national survey conducted by the Ministry of Health, in 2015.[3] This reduction was initially attributed to the publishing of the Strategic Plan for tuberculosis Control, which was accompanied by effective actions and services that aimed at improving epidemiological and operational indicators related to the disease.[4]

The strategic plan established some goals, such as: (i) 100% of Brazilian municipalities integrated to tackle the disease, (ii) 92% of existing cases diagnosed, (iii) of which at least 85% cured, (iv) reduced incidence in, at least, 50%, and (v) mortality reduction by two thirds; all with deadlines expired in 2007. Moreover, the document stated that abandonment rates of treatment should not exceed 5%.[4] However, the abandonment rate is far from the established targets – already including the observed decrease –, which emphasizes the need for implementing new systematic strategies related to the operation of the strategic plan, such as: (i) directing the attention to intermediate and peripheral reasons for abandonment, (ii) routine insertion of popular education, (iii) establishment of intersectoral networks

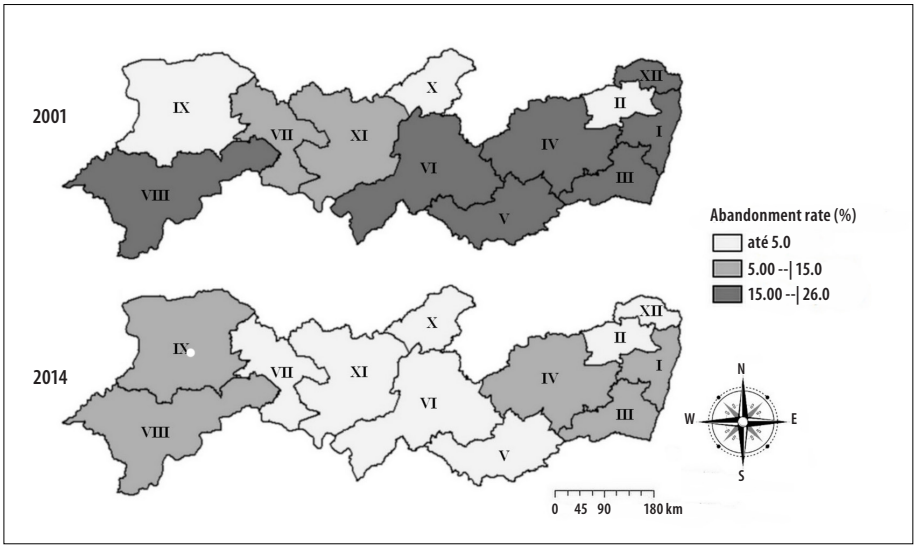

Figure 2 – Abandonment rates (%) of tuberculosis treatment in the Regional Administrations of Health in the state of Pernambuco, Brazil, in 2001 and 2014

Table 1 – Distribution of cases treated, of neglected cases and abandonment rates of tuberculosis treatment according to sociodemographic characteristics in the state of Pernambuco, Brazil, 2001-2014

Variables	Treated cases [a]		Abandoned cases [b]	Abandonment rate
	n	%	n	%
Sex				
Male	37,335	65.5	4,446	11.9
Female	19,665	34.5	2,025	10.2
Ignored/blank	15	0.0	2	13.3
Age (in years)				
≤9	1,642	2.9	197	11.9
10-19	4,242	7.4	459	10.8
20-39	25,824	45.3	3,303	12.7
40-59	18,021	31.6	1,904	10.5
60-79	6,325	11.1	518	8.1
≥80	961	1.7	92	9.5
Education level				
Illiterate	9,849	17.3	1,125	11.4
Incomplete middle school	21,231	37.3	2,580	12.1
Complete middle school	1614	2.8	183	11.3
Incomplete high school	4,840	8.5	449	9.8
Complete high school	2,513	4.4	208	8.2
Incomplete higher education	413	0.7	31	7.5
Complete higher education	1,848	3.2	151	8.1
Not applicable	1,533	2.7	198	12.9
Ignored/blank	13,174	23.1	1,548	11.7
Ethnicity/skin color				
White	11,826	20.7	1,127	9.5
Black	5,599	9.8	746	13.3
Brown	25,497	44.8	2,719	10.6
Asian	943	1.7	109	11.5
Indigenous	240	0.4	32	13.2
Ignored/blank	12,910	22.6	1,740	13.4
Institutional situation				
Not institutionalized	24,514	43.0	2,951	12.0
Prison	2,954	5.2	220	7.4
Nursing home	69	0.1	8	11.5
Orphanage	96	0.2	12	12.5
Psychiatric hospital	198	0.3	25	12.6
Others	1,104	1.9	117	10.5
Ignored/blank	28,080	49.3	3,140	11.8

a) Treated cases: 57,015
b) Abandoned cases: 6,473

coordinated with social assistance, education and culture and also (iv) demand for a more humanized care, in the search for maintaining a relationship with the patient.

Social contexts and life conditions of each region of Pernambuco should be taken into consideration. Due to the territorial heterogeneity, it is clear that the GERES with health responsibility on fewer people present bigger success in maintaining the relationship – such as X Afogados da Ingazeira –, whilst more populous and borderline regions show more difficulties – for instance, I Recife, III Palmares, IV Caruaru, and IX Ouricuri. This difficulty is possibly associated with the increased demand for services and the greater potential for spreading the disease in crowded environments.[4]

Demographic aspects related to sex, age, schooling and ethnicity/skin color observed during the analysis

Table 2 – Information records on special populations among the cases of treatment abandonment in the state of Pernambuco, Brazil, 2001-2014

Special population	Treated cases [a]		Abandoned cases [b]	Abandonment rate
	n	%	n	%
Deprivation of liberty status				
Ignored/blank	56,201	98.6	6,423	11.4
In deprivation of liberty	179	0.3	5	2.7
No deprivation of liberty	635	1.1	45	7.0
Homelessness status				
Ignored/blank	56,264	98.7	6,427	11.4
Homeless	8	0.0	-	-
Not homeless	743	1.3	46	6.1
Health professional				
Ignored/blank	56,267	98.7	6,427	11.4
Yes	4	0.0	-	-
No	744	1.3	46	6.1
Recipient of cash transfer programs				
Ignored/blank	56,645	99.3	6,439	11.3
Recipient	34	0.1	3	8.8
Non-recipient	336	0.6	31	9.2
Immigrant				
Ignored/blank	56,272	98.7	6,427	11.4
Yes	1	0.0	-	-
No	742	1.3	46	6.1

a) Treated cases: 57,015
b) Abandoned cases: 6,473

of the results corroborated with other research surveys conducted in the states of Maranhão,[9, 10] São Paulo[11] and Bahia,[12] which focused on analyzing the recorded notifications from 2001 to 2012. Their findings suggest that the intrinsic cultural aspects to the diversity of the regions have no influence on the demographic characteristics of tuberculosis treatment abandonment cases.

The aforementioned demographic attributes were also found in a survey conducted in the countryside of São Paulo State, in 2015, with the aim of characterizing tuberculosis cases who had evolved to death.[13] Those findings differ mainly in terms of age and education level from research reports carried out in Pará (2016) and Tocantins (2015), which, seeking to define the profile of the general population with tuberculosis, found that this endemic disease was most frequent among individuals over 40 years of age and with over eight years of schooling.[14-16] Thus, it is clear the great similarity between demographic characteristics of cases of abandonment and deaths associated with tuberculosis, to the detriment of the profile of the general population affected by the disease, we can raise the hypothesis of an association between treatment abandonment and death.

The higher abandonment rates observed among young adults is closely linked to social factors, since the population in this age group is more likely to use drugs and alcohol, which is the leading cause of patients non-adherance.[9,17] Such statements are, therefore, in accordance with the findings presented in this study, in a way that it is clear that alcoholics tend to abandon treatment more often.

Low education levels related to abandonment cases can be a determining factor for the lower level of disease awareness and the lack of knowledge on the its severity, and, therefore, of the possibilities of access to treatment. Lack of knowledge on the disease and the false perception of cure are the second cause more associated with abandonment of tuberculosis treatment.[9] Moreover, even having it clarified to the patient, there is no guarantee that such information is sufficiently effective, due to the fragility of care regarding popular health education.[18]

With regard to the social area, a considerable part of the studied individuals were not in institutionalized situation, although users who had institutional ties to psychiatric hospitals or orphanages abandoned treatment more often. Abandonment is less frequent in long-term, controlled

Table 3 – Distribution of the cases treated, neglected cases and abandonment rates of treatment of tuberculosis, according to clinical and epidemiological characteristics in the state of Pernambuco, Brazil, 2001-2014

Variables	Treated cases [a]		Abandoned cases [b]	Abandonment rate
	n	%	n	%
Clinical form				
Pulmonary	48,230	84.6	5,418	11.2
Extrapulmonary	7,009	12.3	804	11.4
Pulmonary + extrapulmonary	1,775	3.1	251	14.1
If extrapulmonary				
Pleural	3,098	5.4	360	11.6
Peripheral lymph node	2,380	4.2	319	12.4
Genitourinary	123	0.2	15	12.1
Bone	435	0.8	52	11.9
Ocular	172	0.3	15	8.7
Miliary	521	0.9	51	9.7
Meningoencephalitis	456	0.8	54	11.8
Cutaneous	147	0.3	21	14.2
Laryngeal	127	0.2	6	4.7
Other	1,086	1.9	127	11.6
Ignored/blank	48,470	85.0	5,453	11.2
Diseases and disorders associated				
AIDS [c]				
Yes	21,173	37.1	735	3.4
No	4,194	7.4	2,197	52.3
Ignored/blank	31,648	55.5	3,541	11.1
Alcohol consumption				
Yes	7,442	13.1	1,153	15.4
No	22,235	39.0	2,328	10.4
Ignored/blank	27,338	47.9	2,992	0.1
Illicit drug				
Yes	31	0.1	4	12.9
No	914	1.6	59	6.4
Ignored/blank	56,070	98.3	6,410	11.4
Smoking				
Yes	99	0.2	8	8.0
No	868	1.5	57	6.5
Ignored/blank	56,048	98.3	6,408	11.4
Diabetes				
Yes	3,264	5.7	256	7.8
No	25,050	44.0	2,954	11.7
Ignored/blank	28,701	50.3	3,263	4.4
Mental illness				
Yes	1,405	2.5	162	11.5
No	26,430	46.3	3,026	11.4
Ignored/blank	29,180	51.2	2,285	7.8
Others				
Yes	4,951	8.7	546	11.0
No	20,021	35.1	2,254	11.2
Ignored/blank	32,043	56.2	3,673	11.4

a) Treated cases: 57,015
b) Abandoned cases: 6,473
c) AIDS: acquired immunodeficiency syndrome

scenarios,[19] for example prisoners, who presented the lowest abandonment rate among the institutionalization subtypes. However, not always is the relationship a synonymous of quality and success in the treatment of tuberculosis; especially in prisons where there is evidence that even with the existence of treatment, the quality of care is poor, reducing the abandonment rate but causing other undesirable situations, such as resistance of the etiologic agent to multiple drugs.[19]

The frequent interruption in the treatment of patients in psychiatric hospitals can be linked to the fact that, after discharge, the user finds it difficult to maintain the treatment, which shows that the health care network is not prepared to offer comprehensiveness of care.[20] Patients from orphanages may be in the same situation, especially those in short-term stay, who, once out of the guardianship of the State or those in welfare organizations, find barriers to continue treatment, or have no interest in maintaining the necessary link to it.[17,20]

Although determinant socioeconomic factors for abandonment have been mentioned, and their importance is recognized by the literature,[21] when we tried to address issues related to social vulnerabilities inherent to special populations, the data available hindered the analysis.

The clinical and demographic characteristics of the study population identified higher abandonment rates among patients diagnosed with pulmonary + extrapulmonary tuberculosis, whilst in exclusive cases of extrapulmonary tuberculosis, the clinical manifestation was ignored in the vast majority of records, making it impossible to check organs and/or affected tissues in non-pulmonary cases. The higher abandonment incidence among pulmonary cases associated with extrapulmonary may reflect the general situation of vulnerability of the user due to multiple consecutive abandonments, which contributed to strengthening and spreading the etiologic agent.[22]

In the context of diseases and associated conditions, there was a high incompleteness in the registry of variables, making it impossible to analyze most aspects. However, it should be noted that the information provided by a study published in 2013 showed a reduction in the incidence and mortality of co-infected with tuberculosis-human immunodeficiency virus.[23,24] The fact is also explained by the introduction of more effective new drug schemes.[23,24]

Besides the analysis of the variables, it is important to mention the high degree of incompleteness of information, essential to the proper situational assessment of health indicators applied to tuberculosis. This problem was also reported by researchers of the spatial distribution of tuberculosis cases in Paraíba, in 2013, when they used information recorded in the notification forms.[25] Insufficient completion of the notification tools suggests fragility in the professional-user communication and operational disruptions in the working process, skills and competences to maintain the relationship with the vulnerable user or carrier of diseases whose treatment requires a long period of time – such as tuberculosis.[26]

Another study conducted in Pernambuco, in 2014, which aimed to analyze the completeness and consistency of records entered on Sinan, mentioned that the deficiency in the quality of data may be related to the fact that much of the welfare professionals consider that filling the notification form is a dispensable activity, with no significant consequences in the practical setting of their work.[27] However, the flawed or incomplete filling of the notification tool can open significant gaps in the analysis and interpretation of data, and, therefore, in the epidemiological knowledge and planning of activities in the various branches of surveillance, prevention and health care.[27]

Although the abandonment rates of tuberculosis treatment have decreased in Pernambuco, they are above the target set in most GERES, especially in urban and surrounding areas. In most of the scientific literature, demographic and clinical-epidemiological factors converge, and there are no great differences among the findings of different Brazilian states. Besides, abandonment was more frequent among cases of pulmonary and extrapulmonary tuberculosis. The similarity between the abandonment profile, here investigated, and the deaths associated with tuberculosis, revealed by other studies, is worrisome and needs to be further investigated.

We suggest health professionals to pay greater attention to maintaining the relationship with patients who fit the profile described in this study. Not only to prevent abandonments, but also to health services to seek a systematic rebuilding of health practices, towards the provision of a care more aligned with ethical principles and the principle of comprehensiveness of SUS, without neglecting patients.

The main limitation of this study is related to the use of secondary data, with a high amount of lack of information on important variables, hindering the characterization of cases according to some aspects, especially social ones.

A suggestion for new researches is the requisite of in-depth analysis of the explanatory variables and social determinants of treatment abandonment under the territorial perspective. The study on the effectiveness of new strategies to approach the issue, such as popular education, continuous professional education, care humanization and food and nutrition assistance to the user in treatment also represents a vast field of knowledge and practice to be explored, aiming the maintenance and improvement of theoretical and empirical instruments necessary for the control and reduction of tuberculosis.

In the context of health services, it is recommended to health managers and surveillance professionals to develop together systematic routines able to transform the possible misconception of the teams on the importance of notification tools for epidemiological surveillance, improving the quality of information for planning, evaluation, control and auditing in Public Health.

Authors' Contributions

Soares MLM, Amaral NAC, Zacharias ACP and Ribeiro LKNP contributed to the conception and design of the study, analysis and interpretation of data, drafting and critical proofreading of the intellectual content of the manuscript and final approval of the version to be published. All authors approved the final version of the manuscript and declared to be responsible for all aspects of the study, ensuring its accuracy and integrity.

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