

# Factors associated with underreporting of tuberculosis based on data from Sinan Aids and Sinan TB

## *Fatores associados à subnotificação de tuberculose com base no Sinan Aids e Sinan Tuberculose*

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**ABSTRACT: Introduction:** Tuberculosis (TB) is one of the world's major public health problems. Epidemiological surveillance has proved to be an important tool to assist in the control and prevention of communicable diseases such as TB and AIDS. This study aimed to estimate the rate and factors associated with the underreporting of TB among cases of coinfection with human immunodeficiency virus (HIV)/AIDS in the state of Pernambuco, based on data from the TB and Aids Notifiable Diseases Information System (Sinan TB and Sinan AIDS). **Methods:** A cross-sectional study was carried out based on the records of the TB and AIDS Notification System to identify cases of TB underreporting in the study period. In order to identify underreporting, a probabilistic linkage was undertaken using ReLink III software. **Results:** The rate of TB underreporting was 29%, and the factors associated were: presenting a clinical form of TB as cavitary or unspecified pulmonary TB or having both kinds of TB at the same time; being treated outside the municipality of Recife; and being treated at health services not specialized for HIV/AIDS. **Discussion:** The proportion of underreporting found in our study was lower than that observed in other Brazilian studies that took into account underreporting from mortality data. **Conclusion:** The variables associated with underreporting of TB were mostly related to the healthcare system rather than to individual characteristics, which points to the need for training of health professionals in order to notify the information systems correctly.

**Keywords:** Tuberculosis. Aids. Disease notification.

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**RESUMO:** *Introdução:* A tuberculose (TB) é um dos graves problemas da saúde pública mundial. A vigilância epidemiológica tem se mostrado uma importante ferramenta para auxiliar em ações de controle e prevenção de doenças transmissíveis, como a TB e a aids. O objetivo do presente estudo foi estimar a proporção e os fatores associados à subnotificação da tuberculose em Pernambuco, entre os casos de coinfeção TB/aids, com base nos dados do Sistema de Informação de Agravos de Notificação da TB e da aids. *Métodos:* Realizou-se um estudo de corte seccional, baseado nos registros dos Sistemas de Notificação de TB e aids, para identificação de casos de subnotificação de TB no período de estudo, mediante a realização de *linkage* probabilístico utilizando o *software* Reclink III. Resultados: Verificou-se proporção de 29% de subnotificação de TB, e os fatores associados à subnotificação foram: apresentar forma clínica da TB pulmonar cavitária ou não especificada, ou ter os dois tipos de TB ao mesmo tempo; e ser atendido fora do Recife e em serviços que não são especializados para vírus da imunodeficiência humana (HIV)/aids. *Discussão:* A proporção de subnotificação encontrada em nosso estudo foi menor do que a observada em outras pesquisas brasileiras que levaram em consideração a subnotificação haja vista os dados de mortalidade. *Conclusão:* As variáveis associadas à subnotificação de TB referem-se, em sua maioria, à rede de atenção, e não às características individuais, o que aponta para a necessidade de capacitação dos profissionais de saúde para efetuar a notificação aos sistemas de informação.

*Palavras-chave:* Tuberculose. Aids. Notificação de doenças.

## INTRODUCTION

Tuberculosis (TB) is a serious public health problem, accounting annually for about 1.5 million deaths from the disease<sup>1,2</sup>. Coinfection by Human Immunodeficiency Virus (HIV) and TB bacillus represents a major challenge for the control of these diseases, and it has been observed that among TB-related deaths in 2015, approximately 0.4 million (28.6%) were a result of its association with HIV<sup>3</sup>. Brazil is included in the list of countries with the highest TB/HIV burden in the world<sup>4</sup>, and the state of Pernambuco ranks third among the federated units with the highest incidence of TB in Brazil (46.4/100,000 inhabitants)<sup>3</sup>.

Epidemiological surveillance, particularly the Sinan Information System, has proven to be an important tool to help control diseases such as TB and AIDS<sup>5</sup>. The data provided by this system allow tracing of the epidemiological profile of TB in the population, as well as to identify cases of HIV-TB coinfection and the risk factors associated with this event<sup>5</sup>. As of 2014, TB cases with HIV-positive test have also been reported in the system, as well as those with the disease's manifestation (AIDS)<sup>6</sup>.

The World Health Organization (WHO) recommends the concomitant start of antiretroviral therapy and treatment for TB in order to reduce mortality in people with this comorbidity<sup>7</sup>. A major disadvantage to the patient who is not notified for TB is the possibility of not starting their treatment in a timely manner, since clearance of the drug is made through the mandatory submission of the notification<sup>2</sup>. In order for estimates of disease magnitude to be made with the highest consistency and credibility, notification needs to

occur in a timely and correct manner<sup>8</sup>. To this end, there are mechanisms that can help in the identification and complementation of the notification data, such as the relationship between databases.

This study aimed to verify the rate of underreporting of TB in Sinan TB among patients with TB/HIV comorbidity identified by Sinan Aids, as well as the factors associated with this underreporting in the state of Pernambuco.

## METHODS

This is a cross-sectional study to estimate the rate and factors associated with underreporting of TB in Sinan, from 2001 to 2010, in the state of Pernambuco, Brazil. Only the AIDS notification was used, since HIV reporting was not yet compulsory in the study period. Data collection was carried out throughout the months of January to June 2012, to ensure that the records of the study period were properly completed.

In order to evaluate the underreporting of TB (dependent variable), a case of TB underreporting was defined as a record in Sinan Aids with TB reported in the item "Associated infections", but not reported in Sinan TB.

The study population comprised all case reporting records in the Sinan TB database in the state of Pernambuco during the period from 2001 to 2010, and in Sinan Aids in the same period.

The information investigated relates to TB and AIDS comorbidity. Initially, the duplicity detection analysis (concept used for situations in which the same patient is reported more than once by the same or another health unit) was performed in the two databases, according to the routine developed by Bierrenbach et al.<sup>9</sup>.

After the duplicities were identified, the linkage series was carried out through the two databases (Sinan TB and Sinan AIDS). The probabilistic linkage was performed using the RecLink III software<sup>10</sup>, with a multi-step routine in which, at each step, a blocking key was used from the combination of the fields: soundex code of the first and last name, gender, year of birth and municipality of residence. In all, 18 blocking strategies were used with several reorganizations of these variables, starting from a more restricted to a less specific blocking key. To compare records, the following fields were used: full name of the patient, mother's name and date of birth. The variables applied to calculate the scores showed a degree of completeness of at least 90%, so that there was no loss in the comparison process. Manual peer review was performed for every step to ensure process quality.

For the identification of the factors associated with underreporting of TB through Sinan AIDS data, individual and health-related independent variables were studied, selected by the theoretical model and with information completeness  $\geq 80\%$ , as presented in Chart 1.

Multivariate logistic regression was performed with all variables with association to outcome  $p < 0.20$  in the bivariate analysis, and adjusted odds ratios (OR) and 95% confidence

intervals were calculated. The inclusion of the variables was done one by one, following the order of statistical association with the outcome in a forward stepwise procedure, using the ratio of veromaxis similarity, with associations whose p value was less than 0.05 being considered significant.

This project was approved by the Research Ethics Committee of the Aggeu Magalhães Research Center (CPqAM) of the Oswaldo Cruz Foundation (Fiocruz).

## RESULTS

The Sinan AIDS database presented 9,350 records regarding the notifications made in the period from 2001 to 2010, in the state of Pernambuco. Of these, 307 were duplicate records (same patient reported more than once) and were removed before probabilistic linkage, resulting in 9,043 records without duplicity. We also excluded 7,736 records not reporting TB at the time of notification. There were 1,307 cases of AIDS with report of TB at the time of notification, and these records continued into the process of relating both databases.

The Sinan TB database presented 51,488 records with notifications of the disease from 2001 to 2010 in the state of Pernambuco, of which 4,846 were duplicates and were removed before probabilistic linkage, resulting in 46,642 unique TB records that were used in the following step of the analysis.

Chart 1. Categorization of individual independent variables and those related to the health service.

Individual variables	
Age Group (years)	< 40 ≥ 40
Sex	Female Male
Clinical form of tuberculosis	Disseminated/extrapulmonary/non-cavitary TB Cavitary or unspecified pulmonary TB Pulmonary and disseminated TB
Municipality of residence	Recife Others
Variables related to the health service	
Quinquennium of care	Second quinquennium First quinquennium
Municipality of care	Recife Others
Care unit	SAE Others

TB: tuberculosis; SAE: Specialized Care Services.

The linkage between 46,642 Sinan TB records and 1,307 Sinan AIDS records showed 926 pairs (71% of the AIDS registries). These pairs represent individuals who were reported in both Sinan TB and Sinan AIDS from 2001 to 2010, while 381 (29%) records in Sinan AIDS with coexistence of TB were not found by the probabilistic relationship in Sinan TB, representing records with TB underreporting.

Among the variables studied, underreporting was more frequent for individuals aged under 40 years, males, who had cavitary or unspecified pulmonary TB, who were not residents of the capital, who were treated in the second quinquennium of the study period in Specialized Care Services (SAEs) of the Municipality of Recife. For the group with no underreporting, the characteristics were similar, differing only by the city of residence, with Recife being more prevalent (Table 1).

Table 1 shows, in addition to the frequency distribution of the variables, the result of the bivariate analysis of the association between individual factors and health services and underreporting of TB. It was verified that the variables age group, sex, clinical form of TB, municipality of residence, quinquennium of care and unit of care were associated with underreporting of TB, with *p* inferior to 0.20. Table 2 shows the final multivariate logistic regression model of the association between individual and health service factors and underreporting of TB. Cases of cavitary or unspecified pulmonary TB, as well as the presence of both forms at the same time, reported in municipalities outside the capital and in services that are not specialized for HIV/AIDS remained associated with underreporting of TB.

## DISCUSSION

The proportion of TB underreporting based on data from Sinan TB and Sinan AIDS in the state of Pernambuco, for the period from 2001 to 2010, was 29%.

Studies on the underreporting of TB through the linkage between Sinan TB and Sinan Aids were not found in the literature. The only study on the coinfection found incomplete information on comorbidities<sup>11</sup>; however, in this study, the authors classified the underreporting of TB/AIDS comorbidity taking as reference the pairs found in the linkage that were considered the gold standard of the proportion of comorbidity, as considered as underreporting those linkage records in which the question regarding comorbidity was not filled. Here, in a different fashion, cases that did not appear in the linkage were viewed as underreporting of TB, considering records in Sinan AIDS that also reported TB as the gold standard.

Other published studies compared Sinan with the Mortality Information System (SIM). Oliveira et al.<sup>12</sup> found 39.4% of TB underreporting in Sinan in Brazil when compared with SIM, a higher number than that evidenced in this study, when comparing Sinan TB and Sinan AIDS. Two studies in the state of Rio de Janeiro that aimed to verify the underreporting of TB in Sinan through SIM data reached a proportion of 44.8% of TB

Table 1. Univariate analysis of the association between individual factors and factors related to health services and the underreporting of tuberculosis based on data from Sinan AIDS, Pernambuco, Brazil, 2001–2010.

	Frequency		OR (CI)	p-value
	Underreporting	Reporting on Sinan TB and AIDS		
	n (%)	n (%)		
<b>Age group (years)</b>				
< 40	255 (30.3)	587 (69.7)	1.0	0.0954
≥ 40	116 (25.9)	332 (74.1)	0.8 (0.6 – 1.0)	
Total	371	919		
<b>Sex</b>				
Female	131 (32.5)	272 (67.5)	1.0	0.0764
Male	250 (27.6)	654 (72.3)	0.8 (0.6 – 1.6)	
Total	381	926		
<b>Clinical form of tuberculosis</b>				
Disseminated/extrapulmonary/non-cavitary TB	115 (23.9)	366 (76.1)	1.0	0.0030
Cavitary or unspecified pulmonary TB	234 (31.7)	505 (68.3)	1.5 (1.1 – 1.9)	
Pulmonary and disseminated TB	32 (36.8)	55 (63.2)	1.8 (1.1 – 3.0)	0.0130
Total	381	926		
<b>Municipality of residence</b>				
Recife	153 (24.1)	483 (75.9)	1.0	0.0001
Others	228 (34.0)	443 (66.0)	1.6 (1.3 – 2.1)	
Total	381	926		
<b>Quinquennium of care</b>				
Second quinquennium	203 (27.6)	533 (72.4)	1.0	0.1569
First quinquennium	178 (31.2)	393 (68.8)	1.2 (0.9 – 1.5)	
Total	381	926		
<b>Municipality of care</b>				
Recife	358 (28.6)	896 (71.4)	1.0	0.0385
Others	22 (42.3)	30 (57.7)	1.8 (1.0 – 3.2)	
Total	380	926		
<b>Care unit</b>				
SAE	278 (26.0)	790 (74.0)	1.0	0.0000
Others	93 (41.3)	132 (58.7)	2.0 (1.5 – 2.7)	
Total	371	922		

TB: tuberculosis; OR: odds ratio; CI: confidence interval; SAE: Specialized Care Services.

underreporting in Sinan in a municipality from the metropolitan area of Rio de Janeiro<sup>13</sup> and 43.2 % for the capital<sup>14</sup>.

It is observed that TB underreporting by mortality data presents a worse condition than that observed in this study, which took as reference the record of TB at the time of AIDS diagnosis. A possible hypothesis for this situation is that, in many cases, the diagnosis of TB is concomitant with that of AIDS, and thus, notifications are carried out together, which could favor the correct notification of both diseases. In addition, studies have demonstrated a great number of diagnoses were given at the time of death, which would explain the lack of notification<sup>15-17</sup>.

There is also a study on the linkage between Sinan TB and the Hospital Admissions System of the National Health System (SIH/SUS), which found a proportion of TB underreporting of 22.1% in 2004 in the state of Rio de Janeiro<sup>14</sup>. The value found is very close to that found in our study, since both deal with the notification of live cases. Studies that establish comparisons with SIM usually present a higher proportion of notifications due to the severity of the cases that led to death, as well as the difficulty of diagnosing TB previously. The use of linkage with the mortality database is in fact an important procedure to detect cases of TB that were not reported or notified at the time of death; however, only serious cases would be found. Otherwise, Sinan TB's linkage with other databases, such as Sinan AIDS, brings the added value of locating patients before cases become serious, and acting to prevent more serious outcomes.

It is worth remembering that the data in this study were based on the records of AIDS notification, but these records also reveal a large percentage of underreporting, as evidenced in the study by Gonçalves et al. carried out in Fortaleza, which found a notification

Table 2. Multivariate analysis of the association between individual factors and factors related to health services, and underreporting of tuberculosis based on data from Sinan AIDS, Pernambuco, Brazil, 2001-2010.

	Odds ratio (95%CI)	p-value
Clinical form of tuberculosis		
Disseminated/extrapulmonary tuberculosis	1.0	
Cavitary or unspecified pulmonary tuberculosis	1.5 (1.2 – 2.0)	0.002
Both forms above	1.8 (1.1 – 3.0)	0.022
Municipality of care		
Recife	1.0	0.000
Others	1.7 (1.4 – 2.2)	
Care unit		
SAE for HIV/AIDS	1.0	0.000
Ou Others tras	2.1 (1.6 – 2.9)	

SAE: Specialized Care Services; HIV: human immunodeficiency virus.

variation from 14.1 to 33.1%. This further aggravates the situation, since the baseline data may be under-reported<sup>18</sup>.

Studies in other countries have also found TB underreporting, demonstrating that this is not a problem unique to Brazil. In Greece, reporting TB is mandatory, but studies point to underreporting of 48% based on records from three major hospitals in the country<sup>19</sup>. Another study carried out in Italy found an average underreporting of 69.4% among TB cases<sup>20</sup>. Although underreporting is found in several systems, it is known that underreporting is mainly due to the lack of knowledge of notifiable diseases and problems in the notification flow carried out by health professionals<sup>11</sup>.

Regarding the notification of the TB/AIDS association to Sinan, structural and organizational aspects of the SUS health services and the SINAN workflow may explain a portion of the underreporting of cases to the surveillance system<sup>21</sup>; however, TB in Brazil is a responsibility of primary care. Therefore, there should be no impediment to the reporting or notification of cases<sup>12</sup>. Nevertheless, basic care still presents major challenges for TB control, such as the unsatisfactory decentralization program itself, as well as deficiencies in structure and human resources<sup>22</sup>. Thus, the diagnosis of TB for coinfecting patients is still predominant in hospitals and SAEs.

The chance of underreporting for TB was greater among those diagnosed with cavitory or unspecified pulmonary TB and with both forms of the disease (disseminated/extrapulmonary/non-cavitory and cavitory or unspecified pulmonary TB) at the same time. Extrapulmonary TB has a more complex diagnosis<sup>4</sup> and, once identified, one might think that there is greater concern in notifying it correctly. Thus, the chance of TB being underreported when in other forms would be greater compared to the extrapulmonary type. On the other hand, pulmonary TB is responsible for its transmission and, therefore, more attention should be given to the reporting of these cases and to starting its treatment. These cases are extremely important for the control of TB, as they can put contacts at risk and spread the disease.

Individuals who were treated in municipalities in the countryside or in the metropolitan region were more likely to underreport TB when compared to those seen in the capital. This finding may demonstrate the need for continuous training of professionals to report cases in municipalities in the countryside or in the metropolitan region<sup>11</sup>. Otherwise, cases registered in the countryside, in municipalities with non-computerized health services, may suffer more with delays or loss of the records en route to the State Health Department, leading to the loss of this information. In these cases, the notification form is sent to the regional health center for typing.

AIDS cases reported in units other than SAEs for HIV/AIDS are more likely to underreport TB. HIV/AIDS SAEs are potentially better able to investigate, diagnose, and correctly report coinfections, including TB<sup>23</sup>.

Underreporting of TB represents a major loss as it is a prerequisite for initiating TB treatment<sup>2</sup>. Therefore, it is interesting to know to what extent non-notification is influencing the treatment of TB or whether these individuals, even if not registered, are receiving



adequate treatment, since notification is necessary for the clearance of the drug for the TB treatment. It is important to investigate the significance and repercussion of TB underreporting, and whether there is harm to the individual with non-notified TB, such as non-receipt of treatment, or to surveillance, which, by failing to detect such individuals, may compromise the availability of drugs for the treatment of patients with TB, as well as the control of the spread of the disease among contacts.

One limitation of the present study is the lack of a gold standard of comparison. Therefore, the estimates presented are based on the assumption that the data contained in the TB and AIDS notification forms are correct. However, it is not possible to rule out the presence of classification bias due to the error in filling Sinan's records.

Nevertheless, the results found are of great importance for the epidemiological surveillance system. The factors associated with the non-notification of TB cases in Sinan TB among the cases of comorbidity registered in Sinan AIDS refer, for the most part, to characteristics related to the health unit and to the care network, rather than to the individual characteristics of the patients. Therefore, more attention to this area could improve data on TB/AIDS coinfection and ensure that estimates are better calculated, being closer to the reality of the service.

## CONCLUSION

The interaction between TB and AIDS control programs is crucial for the control of coinfection. It is recommended that a linkage is carried out between qualitatively different information systems, such as Sinan TB and Sinan AIDS, to complement information on already registered cases of coinfection and to detect cases that were not reported by one of the systems.

More attention should be given to the accurate and effective reporting in order to improve data on TB/AIDS coinfection, thus ensuring that epidemiological estimates are better calculated. In this sense, planning actions in these areas would be carried out more appropriately and accurately.

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