

# Mortality information system for identifying underreported cases of tuberculosis in Brazil

## *Uso do sistema de informação sobre mortalidade para identificar subnotificação de casos de tuberculose no Brasil*

### **Abstract**

The aim of the study was to analyze the underreporting of deaths from tuberculosis (TB) in Brazil, as well as to assess the impact these cases would cause in the reporting rate and proportion of TB deaths in 2006. We analyzed the deaths recorded in the Mortality Information System (SIM) in 2006 and all reports of TB in Brazil during the 2001 to 2006 period. The variables used for the relationship were: report number, city and State of residence, patient name, date and year of birth, sex, mother's name and address. Six blocking steps were performed. Scores above 12.4 were considered pairs, and those below 9.7, doubtful pairs. After each step, we performed a manual review of doubtful pairs. The Reportable Disease Information System (Sinan) had 547,589 records. The SIM had 6,924 records, 39.3% (n = 2,727) of which were not found in Sinan during the period evaluated. We observed that 64.5% (2,707) of deaths were reported in 2006 and after analyzing the proportion of deaths underreported by region and federal units, we found that the highest percentage was in the Northern region, followed by the Southeast and Northeast. The addition of deaths that had not been reported to the Sinan database increased the reporting rate 3.7%. Regarding the proportion of deaths due to TB, such inclusion was responsible for a 60.7% increase in this indicator. The relationship between both databases seems to be an important strategy for improving the quality of the TB surveillance system.

**Keywords:** Tuberculosis. Cause of death. Surveillance. Information systems. Underreporting. Probabilistic record linkage.

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## Resumo

O objetivo desse trabalho foi analisar a subnotificação dos óbitos por tuberculose (TB) no Brasil, assim como verificar o impacto que esses casos causariam na taxa de notificação de casos novos e proporção de óbitos por TB em 2006. Foram analisados os óbitos registrados no Sistema de Informação sobre Mortalidade (SIM) no ano de 2006 e todas as notificações de TB do país no período de 2001 a 2006. As variáveis utilizadas para o relacionamento foram: número da notificação, município e UF de residência, nome do paciente, data, ano de nascimento, sexo, nome da mãe e endereço. Foram realizados seis passos de blocagem. Os escores superiores a 12,4 foram considerados pares, enquanto os inferiores a -9,7, não-pares. Ao final de cada passo, foi realizada a revisão manual dos pares duvidosos. O Sistema de Informação de Agravos de Notificação (Sinan) dispunha de 547.589 notificações, enquanto o SIM tinha 6.924 registros. Desses, 39,4% (n = 2.727) não foram encontrados no Sinan no período avaliado. Observou-se que 64,5% (2.707) dos óbitos foram notificados em 2006 e, ao analisar a proporção de óbitos subnotificados por região e unidades federadas, verificou-se que o maior percentual foi na região Norte, seguida das regiões Sudeste e Nordeste. O acréscimo dos óbitos que não foram relacionados à base de dados do Sinan eleva a taxa de notificação de casos novos em 3,7%. Quanto à proporção de óbitos por TB, essa inclusão foi responsável pelo aumento em 60,7% desse indicador. O relacionamento entre bases de dados configura-se como uma estratégia importante para a melhoria da qualidade do sistema de vigilância da TB.

**Palavras-chave:** Tuberculose. Causa de morte. Vigilância. Sistemas de informação. Subnotificação. Relacionamento probabilístico de registros.

## Introduction

Brazil is among a group of 22 countries that account for 82% of the world's tuberculosis (TB) cases and has 35% of the cases reported in the Americas<sup>1</sup>.

According to estimates by the World Health Organization (WHO), Brazil has an annual incidence of 43 cases per 100 thousand inhabitants (85 thousand new cases per year), an incidence for the smear-positive pulmonary form of 26/100 thousand inhabitants (49 thousand new cases per year), and a mortality rate of 2.6/100 thousand inhabitants (5 thousand cases per year). However, in 2010, according to data submitted by the National Tuberculosis Control Program (PNCT) to the WHO, the notification rate for new TB cases in Brazil was 38/100 thousand inhabitants (approximately 72 thousand new cases) for all forms, 20/100 thousand inhabitants for smear-positive pulmonary TB (approximately 35 thousand new cases), and a death notification rate of 2.5/100 thousand inhabitants (4.8 thousand deaths). Based on this difference, WHO estimates that Brazil had a detection rate of 88% in 2008<sup>1</sup>.

To reach the targets estimated by the World Health Organization, it is necessary to identify the bottlenecks in TB surveillance to determine at what moment the TB cases are not being captured (and thus not being reported).

Failure to report a case of a disease of compulsory notification refers to a case that meets the criteria set by surveillance and that has been identified by a health professional, but has not been reported to the public health service, thus reflecting the health service's incapacity to capture the event<sup>2</sup>.

Brazil's Information System for Notifiable Diseases (SINAN) is the principal instrument in the country for collecting and analyzing national TB data<sup>3</sup>. However, other public systems allow obtaining epidemiological and socio-demographic information to support various public management levels in setting priorities aimed at

TB prevention and control. The Mortality Information System (SIM) was created in 1975 to obtain regular and comprehensive mortality data in Brazil through the completion of Death Certificates<sup>4</sup>. Considering that TB mortality and case-fatality are important parameters for evaluating the severity of the endemic, delays in case detection and initiation of treatment and problems with effectiveness, use of the SIM is extremely important for evaluating the TB surveillance system<sup>5</sup>.

The aim of the current study was to analyze underreporting of TB deaths in Brazil by region and State and the impact of these cases on the notification rate for new cases and TB case-fatality.

## Methods

We selected deaths that occurred in Brazil and were recorded in the SIM database in the year 2006 with TB codes (ICD-10 – 10<sup>th</sup> revision, A15 to A19) as underlying or associated cause. The SINAN data used in this study consisted of all TB reports in the country with the reporting year included from 2001 to 2006. TB cases ending in death and that were not reported were defined as those for which the year of death was 2006 and which had not been recorded in the SINAN database from 2001 to 2006, that is, up to five years prior to the year of death, according to the definition of new case from the Ministry of Health epidemiological surveillance guidelines<sup>6</sup>. Access to the databases was kindly provided by the Department of Situational Health Analysis (DASIS) and the National Tuberculosis Control Program (PNCT) of the Ministry of Health.

The TB information system allows patients to be reported several times over the course of their lives. Multiple entries of the same case may assist surveillance of the disease, but can also generate countless duplicate records in a mistaken way. The identification and removal of these records were performed in two steps: true duplicate entries were removed using the algorithm developed by Bierrenbach et al. (2007),

which conserves the repetitions referring to cases of relapse and reentry after drop-out for subsequent analyses with SINAN; starting with this base, the remaining repetitions were eliminated, maintaining only the oldest notification for analysis of under-recording.

Since the databases used in this study do not have a univocal identifying field, the probabilistic record linkage method was used. Based on the combined use of common fields present in the respective databases, one estimates the probabilities that given records in the two databases belong to the same persons. Thus, it is possible to verify the likelihood that a pair of records refers to the same individual<sup>8,9</sup>.

Linkage used the third version of the Reclink program<sup>10</sup>. The variables used to perform the linkage were: notification number, municipality (county) of residence, State of residence, patient's name, birth date, sex, mother's name, street name, street number, apartment number, neighborhood, and year of birth. Six blocking steps were performed sequentially with the combination of fields. The starting point was a more restricted key, with a subsequent decrease in the restriction, seeking to minimize the loss of pairs, i.e., the occurrence of false-negatives:

1 - *Soundex* (first name) + *soundex* (last name) + sex + State of residence; 2 - *Soundex* (first name) + sex + State of residence; 3 - *Soundex* (last name) + sex + State of residence; 4 - *Soundex* (first name) + sex; 5 - State of residence + sex; 6 - Municipality of residence + sex.

For comparison and calculation of scores, all the steps used the following fields: patient's name, mother's name, and birth date.

An estimate of parameters was performed by applying the Expectation Maximization (EM) algorithm. This technique makes use of maximum likelihood of missing data and allows the identification of individuals that are common to different databases according to their characteristics<sup>11</sup>. The following parameters were thus used for each automated step: patient's name

(hit probability: 97.7984; miss probability: 0.00158924), mother's name (hit probability: 75.3206; miss probability: 0.00820691), and birth date (hit probability: 96.5851; miss probability: 1.67448).

The maximum and minimum limits set for the scores were 19.7907 and -12.3714, respectively. Scores above 12.4 were considered pairs, while those below -9.7 were considered non-pairs, while the rest remained as doubtful pairs.

A manual revision of the doubtful pairs was performed at the end of each step by a single researcher, according to the following tiebreaking criteria: patient's name, mother's name, birth date, and municipality of residence. The other variables were used in the visual comparison to assist classification of the pairs when the presence of missing fields prevented classifying the pair. A list of neighboring municipalities along the borders between Brazilian States was used during the manual revision to aid classification of a pair as belonging to the same individual when there was disagreement between residential addresses between the records for a possible true pair.

We opted to define as a pair a paired record that remained doubtful after the manual revision process, in the sense of minimizing false-negative errors. Thus, the observed results can be interpreted as a conservative estimate of the underreporting of deaths.

We calculated the proportion of underreporting of deaths from/with TB for Brazil as a whole and by State. To verify whether the inclusion of cases retrieved from the SIM modifies the national TB indicators, we calculated the original and corrected notification rate for new TB cases and the proportion of new TB cases ending in death. The original notification rate was calculated by dividing the total number of new TB cases reported in 2006 by the number of inhabitants in the same year, multiplied by 100,000. The corrected notification rate was calculated by adding to the numerator of the original rate the deaths that occurred in 2006 and that were not recorded in the

SINAN database. The estimated population was taken from the DATASUS website<sup>13</sup>. The proportion of new TB cases ending in death was calculated by adding those ending in death and deaths from other causes in 2006, divided by the total number of reported new cases, in the case of the original indicator. For the corrected indicator, we added into the numerator and denominator the number of unreported cases retrieved from the Mortality Information System.

Data processing and analysis used the software programs EpiInfo [TM] version 3.3.2 and Stata version 9.0<sup>®</sup>. The study was approved by the National Commission on Research Ethics (CONEP) on April 12, 2009.

## Results

SINAN included 571,336 TB notifications from 2001 to 2006. Removal of duplicate entries left 547,589 notifications (95.8%). The Mortality Information system had 6,953 records that presented TB as one of the causes of death in the year 2006. Twenty-nine records from the Mortality Information System were excluded because the name, mother's name, and address had not been completed or had been completed incorrectly, to the point of impeding the linkage process.

A total of 5,569 pairs were found through linkage of the Mortality Information System with SINAN: 4,493 pairs (83.7%) were found in the first blocking key, 623 (11.6%) in the second, and 121 (2.3%) in the fifth step (Table 1).

After elimination of the repeated pairs generated by the Mortality Information System records that formed pairs more than once (cases of relapse or reentry, for example), a total of 4,197 pairs were identified. Of the 6,924 TB death records analyzed, 39.3% (n=2,727) were not found in the SINAN database from 2001 to 2006.

Of the total TB deaths recorded in the Mortality Information System in 2006 that were paired with the TB notifications in SINAN, 64.5% (2,707) were reported in the same year, 16.8% (705) in the previous year,

**Table 1** - Proportion of pairs found according to the blocking steps in the probabilistic record linkage between the SIM (2006) and Sinan (2001-2006) - Brazil.

**Tabela 1** - Proporção de pares encontrados segundo os passos de blocagem no relacionamento probabilístico entre o SIM (2006) e o Sinan (2001 a 2006) - Brasil.

Blocking Steps	N	%
Step 1: Soundex (first name) + Soundex (last name) + sex + State	4,493	83.7
Step 2: Soundex (first name) + sex + State	623	11.6
Step 3: Soundex (last name) + sex + State	0	0.0
Step 4: Soundex (first name) + sex	40	0.7
Step 5: sex + State	121	2.3
Step 6: sex + municipality of residence	92	1.7
<b>Total</b>	<b>5,369</b>	<b>100.0</b>

6.6% (277) in 2004, and 12.1% (508) from 2001 to 2003. Analysis of the proportion of unreported deaths stratified by State showed the highest percentage in the North, followed by the Southeast and Northeast of Brazil. The South showed a lower underreporting rate, despite having more total TB deaths than the North.

This indicator behaved differently not only between regions, but also between States in the same region, with variations ranging from 16.6% to 54.5% in the same region (Table 2). Rondônia, Amapá, and Paraíba showed values greater than 50%, and in 12 States this proportion was higher than the Brazilian national mean. The lowest values were in Paraná (23.4%), Mato Grosso do Sul (20.7%), Santa Catarina (19.1%), and Roraima (16.6%).

Adding the deaths that were not linked to the SINAN database would increase the notification rate for new TB cases in the year 2006 by up to 3.7%. It would also increase the TB case-fatality rate by 60.7%, increasing from 5.6% to 9.0% in that same year (Table 2). These increases differed between States, i.e., from 1.5% to 7% for the notification rate of new cases and from 18.4% to 130.7% for cases reported in SINAN and ending in death.

## Discussion

The high proportion of underreporting and changes in the proportion of deaths and

in the notification rate for new cases due to the inclusion of deaths on case records were the main results of this study.

Since death is a final outcome for TB cases, the fact that 39.4% of deaths from TB or associated with it fail to appear in the case records points to an evident mismatch between TB epidemiological surveillance and TB care, since they represent severe cases that were not reported, even at the time of death. This also reflects the low coverage of the TB epidemiological surveillance system, corroborating other Brazilian and international studies that linked mortality records and case records<sup>14,15,16,17</sup>.

Problems related to access and diagnosis should also be taken into consideration. Deaths due to TB may be considered a sentinel event, a concept defined as the occurrence of an avoidable disease, disability, or death, which can reveal the individual's high vulnerability due to low socioeconomic, occupational, or environmental status or adverse health conditions such as lack of adequate or timely action by health services<sup>18,19</sup>.

Unemployment, low schooling, and low income are individual factors that increase vulnerability to TB and may thus also influence access to health services as well as to quality diagnosis<sup>20,21</sup>. Since TB is historically associated with poverty, individuals with more schooling may not be diagnosed correctly, as discussed by Sousa and Pinheiro<sup>22</sup>. In addition, contextual aspects may be

**Table 2** - Comparison of the indicators, new TB cases reporting rate and proportion of TB cases closed as death, before and after the inclusion of non-reported deaths in Sinan. Brazil, 2006.

**Tabela 2** - Comparação dos indicadores taxa de notificação dos casos novos de TB e proporção de casos de TB com encerramento óbito antes e depois da inclusão dos óbitos não notificados no Sinan. Brasil e unidades federadas (UF), 2006.

State	Unreported Deaths		Notification rate			% Ending in death		
	N	%	Original	Corrected	Change (%)	Original	Corrected	Change (%)
RO	18	55.6	27.5	28.7	4.2	4.4	8.3	86.9
AC	8	32.0	50.7	51.8	2.3	6.3	8.4	33.3
AM	45	36.9	65.4	66.8	2.1	4.2	6.2	45.9
RR	2	16.6	31.2	31.7	1.6	6.3	7.8	23.0
PA	97	46.0	47.3	48.6	2.9	3.8	6.5	72.0
AP	7	53.8	36.2	37.4	3.1	4.9	7.8	58.7
TO	6	33.4	16.9	17.3	2.7	3.6	6.1	70.5
MA	83	41.5	41.2	42.5	3.3	6.4	9.4	46.2
PI	41	45.0	32.2	33.5	4.2	4.2	8.1	91.9
CE	158	47.8	42.7	44.6	4.5	3.3	7.5	126.0
RN	20	33.4	33.0	33.6	2.0	3.1	5.0	61.3
PB	69	53.0	27.2	29.1	7.0	4.8	11.0	130.7
PE	145	31.3	47.7	49.4	3.6	8.1	11.3	39.1
AL	44	44.0	36.6	38.1	3.9	6.2	9.7	57.6
SE	18	31.5	27.8	28.7	3.2	5.9	8.9	49.7
BA	244	44.2	43.5	45.3	4.0	5.5	9.2	66.4
MG	157	35.4	23.9	24.7	3.4	8.7	11.7	34.2
ES	37	36.7	34.6	35.6	3.1	7.7	10.5	36.0
RJ	511	44.2	74.3	77.5	4.4	3.9	8.0	104.3
SP	621	41.5	36.4	37.9	4.2	3.9	7.8	97.4
PR	64	23.5	23.5	24.1	2.6	9.4	11.7	24.8
SC	23	19.2	25.0	25.4	1.5	6.0	7.5	23.6
RS	200	32.7	39.1	40.9	4.7	8.2	12.3	50.1
MS	16	20.7	34.9	35.6	2.0	9.6	11.4	18.4
MT	49	44.5	40.3	42.0	4.3	5.6	9.5	68.2
GO	36	36.4	14.9	15.5	4.2	5.6	9.4	67.9
DF	8	44.5	15.7	16.1	2.1	4.3	6.3	46.9
<b>Brazil</b>	<b>2,727</b>	<b>39.4</b>	<b>37.4</b>	<b>38.8</b>	<b>3.7</b>	<b>5.6</b>	<b>9.0</b>	<b>60.7</b>

related to the use of health services. The first is the supply of health care or services by States and municipalities. Considering that in Brazil, TB is a disease that falls under the responsibility of primary care and that timely uptake of cases does not require high-complexity care, there should be no obstacles to access. However, a TB control program that fails to recommend active

case search in the community or in health units (a basic strategy to increase case uptake) may present flaws in surveillance of the disease and underreporting of cases. Another hypothesis for the occurrence of underreporting could relate to the volume of reported cases. The highest proportion of reported TB cases occurs in the Southeast (45%) and Northeast regions (29%), which

also appeared in this study with the highest underreporting rates<sup>23</sup>. This result corroborates the findings by Braga, who noted that these regions had numerous municipalities with apparently insufficient TB control activities, indicating the existence of TB underreporting and precarious functioning of State TB control programs<sup>24</sup>.

However, the indicator's variation between States of Brazil calls attention to other factors which may have influenced this finding. The fact that two States from the same region (Rondônia and Roraima), with similar epidemiological, demographic, and cultural characteristics, presented discordant values may be explained in part by the deficient coverage of the Mortality Information System. The North and Northeast regions presented less than 80% coverage in the target year. Coverage in Rondônia was less than in Roraima, suggesting that cases may not be captured even by the Mortality Information System, generating lower underreporting rates<sup>25,26</sup>. However, in States with high coverage rates, like Rio de Janeiro and Rio Grande do Sul, worrisome values were found. The proportion of TB cases received and diagnosed in hospitals (a common situation in the country's large State capitals) should be taken into account to improve underreporting. According to Selig et al., 49% of TB deaths from September 2005 to August 2006 in two public general hospitals with open emergency departments in Rio de Janeiro were not recorded in the SINAN database from 1995 to 2006<sup>27</sup>. Recording error for causes of death in the Mortality Information System might explain part of the under-recording. However, this hypothesis appears less convincing to the extent that attributing a TB diagnosis to cases without proof appears unlikely.

Structural and organizational issues in the health services, the SINAN flowchart, and the organization of the Unified National Health System (SUS), as described by Ferreira et al., may explain part of the underreporting of TB cases to the surveillance system<sup>28</sup>. Although the data flow is

documented by Ministry of Health and is known to all the States of the country, each municipality (county) adds minor modifications to this flow according to its local reality, while the health units create their own shortcuts, which can produce unfavorable results.

The addition of unreported deaths to the SINAN database can impact important epidemiological indicators for the Program. The new TB case notification rate and the proportion of TB deaths among cases reported in the year 2006 were considerably modified for the country. The increases in these two indicators differed greatly between States, with variations greater than fivefold between the smallest and largest increases. This result points to different degrees of implementation of TB surveillance in Brazil.

By correcting the proportion of cases ending in death, one-fourth of the States practically doubled their original value. Interestingly, this list includes Rio de Janeiro and São Paulo, with a major portion of the country's TB burden<sup>29</sup>, which leads one to assume greater experience with case surveillance, not demonstrated in this study.

While the elimination of double entries in the SINAN database led to a 6.3% reduction in the TB incidence rate in Brazil in 2006<sup>12</sup>, the inclusion of unreported deaths increased this rate by 3.7%. Other national information systems in Brazil record TB cases, like the Hospital Information System of the Unified National Health System. Record linkage with this database was not one of the current study's objectives, but it could lead to a larger increase in TB incidence<sup>22</sup>.

Probabilistic record linkage between databases is one of the techniques used by many studies to identify underreporting<sup>5,14,15,19,25,30-34</sup>. The probabilistic methodology does not require exact concordance between the values for the pairing variables between two records, which minimizes failure to find the data for the same patient in two different databases. The pairs of records formed that did not have a high score were evaluated by the researcher during the

manual revision of pairs. The occurrence of missing data in the variables used for the linkage and the presence of common names or homonyms may have caused a reduction in the number of pairs formed.

Since TB treatment is provided mainly in the primary healthcare network where links between patients and the health unit should be well-established, TB patients do not normally move between States to obtain treatment. However, to minimize the negative impact of the linkage process, we opted to use the State and municipality of residence in the blocking steps. The adoption of well-defined tiebreaking criteria and the use of a list of neighboring municipalities along State borders to support the manual revision were strategies to minimize possible pairing errors that could occur when patients failed to properly inform their residential address. The strategy of including among pairs the paired records that remained doubtful during the manual revision decreased the likelihood of false negatives, while a 39.4% rate of unreported deaths is a conservative estimate of underreporting of deaths in this study.

Linking the Mortality Information System to five years of the SINAN database and following all the respective blocking steps increased the certainty of the occurrence of underreporting. However, we observed that searching for deaths in the Mortality Information System using only the cases recorded in the two previous years in the SINAN database and processing only the first two blocking steps as routine TB surveillance accounted for a high percentage of retrieval of cases (81.3% and 95.3%, respectively), a strategy that would reduce the workload for services, with a high impact on improvement of TB reporting quality.

The largest proportion of deaths found

in SINAN was reported in the same year as the death (64.5%). This result appears to relate more to the case uptake and late diagnosis, with a reduction in patient survival and treatment efficacy.

The World Health Organization has recommended that quality assessment of notification systems should be done routinely by countries to make the TB epidemiological and operational indicators more trustworthy, thus impacting public health decision-making<sup>29</sup>. TB incidence in Brazil is estimated by multiplying the number of TB deaths in the Mortality Information System by the case-fatality rate (calculated by the number of deaths in the Mortality Information System and the number of cases in the SINAN database, with appropriate adjustments due to the systems' coverage). Case-fatality is calculated by using the linkage between databases, since there is no certainty that the individuals are recorded in both bases<sup>1,34</sup>. Routine use of this technique is important to ensure estimates that as close to reality as possible. However, the introduction of the field for TB death among the closure situations in the SINAN database in 2006<sup>3</sup> simplified calculation of this indicator, facilitating its use in planning TB control activities. Likewise, the use of database linkage helps improve case closure, besides ensuring that a case ending in death is recorded in SINAN.

Linkage strategies are an important tool used by many countries to perform estimates of incidence and number of cases<sup>15,16,35,36</sup>. We thus recommend that the National Tuberculosis Control Program encourage database linkage in order to improve the TB surveillance system and generate more trustworthy indicators to support decision-making.



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