

Completeness of the tuberculosis information system in the state of Paraná, 2008-2017: an ecological study

Completude do Sistema de Informação em Tuberculose no estado do Paraná, 2008-2017: estudo ecológico Integridad del sistema de información sobre tuberculosis en el estado de Paraná, 2008-2017: un estúdio ecológico

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ABSTRACT

Objective: to examine the completeness of tuberculosis data in Brazil's Notifiable Disease Information System (SINAN). **Method:** this ecological study considered notified cases of tuberculosis treated in Paraná between 2008 and 2017. Data were grouped into notification, follow-up and complementary variables and comprised mandatory and essential information. Completeness was classified as excellent (< 5% incomplete), good (5 to < 10%), regular (10 to < 20%), poor (20 to 50%) and very poor (> 50%). The study complies with *Conselho Nacional de Saúde* Resolution 510/2016. **Results:** mandatory variables were less than 5% incomplete, and essentials performed very poorly for sensitivity test, smoking and illicit drugs. Completeness in follow-up information worsened over the years, while other groups improved, except in 2014. **Conclusion:** unsatisfactory completeness in some essential variables, and decreasing completeness in follow-up information, reveal repercussions on bonding between individual and health service, and on case outcomes.

Descriptors: Health Information Systems; Public Health Surveillance; Tuberculosis; Disease Notification.

RESUMO

Objetivo: analisar a completude dos dados de tuberculose no Sistema de Informação de Agravos de Notificação (SINAN). **Método:** estudo ecológico composto por casos notificados de tuberculose tratados no Paraná entre 2008-2017. Os dados foram agrupados em variáveis de notificação, acompanhamento e complementares e compreendiam informações de preenchimento obrigatórias e essenciais. Classificou-se a completude como excelente (<5% de incompletude), boa (5 a <10%), regular (10 a <20%), ruim (20 a 50%) e muito ruim (>50%). A pesquisa atende a resolução 510/2016 do Conselho Nacional de Saúde. **Resultados: v**ariáveis obrigatórias apresentaram menos de 5% de incompletude, as essenciais tiveram avaliação muito ruim para teste de sensibilidade, tabagismo, drogas ilícitas. Completude do grupo acompanhamento piorou ao longo dos anos, demais grupos apresentaram melhora, exceto em 2014. **Conclusão:** completude insatisfatória em parte das variáveis essenciais e diminuição da completude no grupo acompanhamento revela repercussão no vinculo individuo-serviço de saúde e no desfecho dos casos.

Descritores: Sistemas de Informação em Saúde; Vigilância em Saúde Pública; Tuberculose; Notificação de Doenças.

RESUMEN

Objetivo: examinar la integridad de los datos sobre tuberculosis en el Sistema de Información de Enfermedades Notificables de Brasil (SINAN). **Método**: este estudio ecológico consideró los casos notificados de tuberculosis tratados en Paraná entre 2008 y 2017. Los datos se agruparon en variables de notificación, seguimiento y complementarias y comprendieron información obligatoria y esencial. La integridad se clasificó como excelente (<5% incompleta), buena (5 a <10%), regular (10 a <20%), mala (20 a 50%) y muy mala (>50%). El estudio cumple con la Resolución 510/2016 del Conselho Nacional de Saúde. **Resultados:** las variables obligatorias fueron menos del 5% incompletas, y lo esencial tuvo muy mal desempeño en la prueba de sensibilidad, tabaquismo y drogas ilícitas. La completitud en la información de seguimiento empeoró con los años, mientras que otros grupos mejoraron, excepto en 2014. **Conclusión:** completitud insatisfactoria en algunas variables esenciales, y una completitud decreciente en la información de seguimiento, revelan repercusiones en la vinculación entre individuo y servicio de salud, y en resultados del caso. **Descriptores:** Sistemas de Información en Salud; Vigilancia en Salud Pública; Tuberculosis; Notificatión de Enfermedades.

INTRODUCTION

Among the infectious diseases, tuberculosis stands out as one of the most deadly. An estimated 10 million cases of tuberculosis were reported worldwide for the year 2018, with 1.2 million deaths in HIV-negative people¹. In Brazil, 72,788 new cases of the disease were diagnosed in 2018, with an incidence coefficient of 34.8 cases per 100,000 inhabitants².

In 2014, the End TB strategy (for the end of tuberculosis) was approved by the World Health Organization (WHO) and, among the targets of the proposal are reducing by 35% the number of deaths from the disease and its incidence

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rate by 20% by the year 2020 compared to 2015, as well as it stipulates as a goal for the year 2030 the achievement of a 90% reduction in the number of deaths from tuberculosis and an 80% reduction in the incidence rate, based on data from 2015^{1,3}. The cumulative reduction in the global incidence rate in the 2015-2018 period was only 6.3%, whereas the reduction in mortality in the same period was 11%, less than a third of the proposed target¹, causing concern about the capacity of the countries to implement the proposal and about the quality of records in health information systems.

Among the actions planned for tuberculosis control, there is the registration of case information, since the initial search of the cases until the end of the treatment. The timely and qualified record of the data is a fundamental component for the management of cases and for the control of the disease, as it allows: monitoring the trends of the disease, the progress of individual and collective treatment, ensuring care continuity when referral to other health institutions is necessary, monitoring the outcome of the treatment, and allowing for the planning and evaluation of the strategies of the National Tuberculosis Control Program (*Programa Nacional de Controle da Tuberculose*, PNCT) in its several levels⁴.

In this way, the Health Information Systems (*Sistemas de Informação em Saúde*, SIS) are significant instruments for identifying the health situation of a given population since, in addition to characterizing individuals at risk, they also assist in directing and planning public policies according to the needs and singularities of each population group⁵. For the use of the recorded information, it is a requirement to maintain high quality of data, which must be regularly measured, analyzed and improved to meet the needs of the individuals^{6,7}.

One of the attributes integrating the dimension of data quality concerns the completeness of the information, which refers to the proportion of filling in the variables in the notification system⁸⁻¹⁰.

It is worth mentioning that the incompleteness of the notification record and the monitoring of patients with tuberculosis can harm the continuity of the care provided, the exchange of information between the different health care services that assist the patient, and make it difficult to monitor and evaluate the care provided¹¹, in addition to making it questionable whether the care activity that preceded the registration was not actually carried out, or whether it was carried out and was not registered¹², making it difficult to determine whether the failure is in filling in the instruments or in the monitoring of the patients¹³.

Given the above, the present study aimed to analyze the completeness of the data referring to tuberculosis in the Information System for Notifiable Diseases (*Sistema de Informação de Agravos de Notificação*, SINAN) in the state of Paraná, in the 2008-2017 period.

METHOD

This is an epidemiological study, with an ecological approach based on exploratory document analysis¹⁴, carried out in the state of Paraná, southern region of Brazil. The state has 399 municipalities in a territorial area of 199,305,236 km² and an estimated population of 11,433,957 people, with 74.9% covered by primary health care actions^{2,15}, has a Human Development Index (HDI) of 0.749, being considered the 5th best in the country¹⁵.

The study population consisted of tuberculosis cases notified in the SINAN who underwent treatment in the state of Paraná, from 2008 to 2017. The data were provided in July 2019 and are available from the General Coordination of the PNCT, upon a request carried out through the website of the Electronic System of Information to the Citizen (e-SIC), available at the following electronic address: https://esic.cgu.gov.br/sistema/site/index.aspx.

From the database, the necessary variables were selected to perform epidemiological and operational analyses along with the diagnosis, monitoring and outcome of the cases, fundamental for the health services to understand the behavior of the disease.

Every diagnosed case of tuberculosis must be notified through the notification/investigation form of the SINAN¹⁶, which comprises 47 variables divided into four blocks, namely: general data, individual notification, residence data, and complementary data. The first three blocks mentioned include information regarding the notifying unit and the individual, such as personal and housing data. The last block, on the other hand, includes information related to the investigation of the case, such as the type of entry of the person in the information system, the form of the disease, belonging to the special population, and test results, among others.

To update the data referring to the treatment, the case monitoring bulletin is used, which includes information regarding the examined contacts, carrying out the monthly sputum smear microscopy, performing the Directly Observed Treatment (DOT), treatment outcome, etc.

According to the notification form and case monitoring bulletin, the variables were selected and divided into three groups, namely: notification (sociodemographic data), monitoring, and complementary (from the complementary data block of the tuberculosis notification form, comprising related variables the patient's medical history/conditions and the result of diagnostic tests).



The selected variables were also identified as to the type of filling out, in mandatory and essential (Figure 1). The mandatory variables are those that, if they not filled in, it is not possible to insert the notification in the "SINAN", whereas those classified as essential are important for epidemiological and operational analyses; however, their non-filling does not prevent the registration of the case in the Information System¹⁶.

Group of variables	Variables and fill-in classification				
	Mandatory	Essential			
Notification	Gender, pregnant	Race, schooling and area of residence			
Monitoring	-	Second and sixth month sputum smear microscopy, Directly Observed Treatment Short (DOTS) indicated*, DOTS performed and treatment outcome			
Complementary	Type of entry, clinical form, diagnostic smear bacilloscopy test, sputum culture, HIV	Institutionalized*, chest x-ray, associated conditions [AIDS, alcoholism, diabetes, mental illness, smoking, illicit drugs, other], drug sensitivity test**, special population [health professionals***, population deprived of their liberty***, homeless population*** and immigrants***], government benefits***			

*Variables filled until 2014 in the information system; **Variable filled from 2014 onwards; ***Variables filled from 2015 onwards.

FIGURE 1: Group of variables according to the Notification System for Notifiable Diseases and classification regarding the mandatory and essential filling selected for the research. Paraná, Brazil, 2019.

In the data analysis, the R software was initially used to calculate the percentage of incompleteness of each variable studied for the entire state of Paraná, considering the observations from the full study period. The fields not filled in ("empty") or filled in as "ignored" were understood as incomplete data. The latter were transformed into "empty" information using the *Microsoft Office Excel 2016* software. Thus, completeness was classified as follows: excellent (less than 5% incompleteness), good (5%-10%), regular (10%-20%), poor (20%-50%), and very poor (above 50%)¹⁷. To avoid the overlap of the incompleteness values in the "good", "regular" and "poor" categories, adjustments were made in the cut-off points, stipulating as good (5% to <10%) and regular (10% to <20%), as proposed by Lino and Fonseca¹⁸. After this classification, the percentage of incompleteness of each variable was calculated for each year of study and the minimum and maximum percentage of each of them was identified, indicating the years in which they occurred. The median of the percentage of each variable was also calculated.

Finally, the mean of the incompleteness of each group of variables (notification, monitoring and complementary) was calculated, as well as for the state of Paraná by year of study. This was done by adding up the percentages of incompleteness of the variables of each group or state in each year studied, dividing by the number of variables.

The research complies with the determinations described in Resolutions 466/2012 and 510/2016 of the National Health Council and, for being public domain data, with aggregated information without the possibility of identifying the individuals, it is not necessary to process it by the Committee Research Ethics.

RESULTS

The study identified 23,852 notified tuberculosis cases that underwent treatment in the state of Paraná from 2008 to 2017. The completeness of data on tuberculosis from the SINAN in the state as a whole was classified as regular (10.1% of incompleteness). The variables categorized as mandatory obtained excellent completion rates (less than 5% of incompleteness). Related to the essential filling variables, the lowest completeness values corresponded to the Sensitivity Test (ST) (61.0% of incompleteness), smoking (65.4% of incompleteness), and illicit drugs (65.2% of incompleteness) fields (Table 1). In the notification variables, it was identified that the schooling record showed a slight improvement in 2016 when compared to 2010. In the monitoring variables, the control sputum smear microscopy record (2nd and 6th months), as well as the DOTS (both indicated and performed), worsened over time. And in the complementary variables, there was worsening in the registration of AIDS, smoking and illicit drugs (Table 1).



TABLE 1: Completeness of the variables on tuberculosis in the Notifiable Diseases Information System (SINAN) according to the percentage of incompleteness. Paraná, 2008-2017.

Variável	Incompleteness (%)*	Completeness	Min (year)**	Median**	Max (year)**
Notification	. ,				
Gender*** (mandatory)	0	Excellent	0	0	0
Pregnant (mandatory)	0.8	Excellent	0.1 (2017)	0.7	1.9 (2008)
Race	2.5	Excellent	0.8 (2016)	2.7	3.4 (2009; 2011)
Schooling	21.2	Bad	17.4 (2016)	21.6	23.7 (2010)
Zone	2.7	Excellent	1.4 (2010)	3.05	4.3 (2015)
Monitoring					
Sputum smear microscopy 2 nd month	13.7	Regular	8.5 (2010)	13.8	20.1 (2013)
Sputum smear microscopy 6 th month	19	Regular	12.6 (2008)	20.45	26.5 (2013)
DOTS indicated	3.8	Excellent	0.8 (2011)	1.3	20.6 (2014)
DOTS performed	2.4	Excellent	0.3 (2008)	0.65	9.9 (2017)
Treatment outcome	1.1	Excellent	0.0 (2010 a 2012)	0.35	5.8 (2017)
Complementary					
Type of entry*** (mandatory)	0	Excellent	0	0	0
Institutionalized	4.4	Excellent	0.8 (2012)	1.9	21.0 (2014)
Chest X-ray	0.6	Excellent	0.2 (2011)	0.5	1.7 (2017)
Clinical form (mandatory)	0.03	Excellent	0 (2008 a 2016)	0	0.2 (2017)
AIDS	6.7	Good	3.0 (2014; 2015)	4.3	16.1 (2008)
Alcoholism	3.4	Excellent	1.0 (2012)	2.75	7.9 (2008)
Diabetes	3.6	Excellent	1.8 (2012)	2.7	9.00 (2008)
Mental illness	3.5	Excellent	1.5 (2012)	2.95	8.40 (2008)
Smoking	65.4	Very poor	2.2 (2016)	90.3	99.6 (2009)
Illicit drugs	65.2	Very poor	2.8 (2015)	90.1	99.6 (2009)
Other diseases	8.4	Good	5.5 (2014)	7.7	15.3 (2008)
Diagnostic sputum smear microscopy	0.02	Excellent	0 (2008 a 2016)	0	0.1 (2017)
for diagnosis (mandatory)					
Culture (mandatory)	0.02	Excellent	0 (2008 a 2016)	0	0.1 (2017)
Sensitivity testing	61	Very poor	58.5 (2016)	62.25	72.2 (2014)
HIV (mandatory)	0.03	Excellent	0 (2008 a 2013;	0	0.1 (2014; 2017)
			2015; 2016)		
Health professionals	2.2	Excellent	1.1 (2015; 2016)	1.1	3.0 (2017)
PDL	2.1	Excellent	1.1 (2015; 2016)	1.1	2.6 (2017)
Homeless population	2.3	Excellent	1.0 (2015)	1.2	3.1 (2017)
Immigrants	2.3	Excellent	1.1 (2015)	1.2	3.1 (2017)
Government beneficiaries	1.8	Excellent	1.4 (2015)	1.5	3.5 (2017)

Key: DOTS – Directly Observed Treatment Short; PDL – Person Deprived of Liberty.

*percentage of incompleteness of each variable, calculated considering all the observations from the state of Paraná for the entire study period; **minimum, median and maximum values were identified considering the annual calculation of the incompleteness of each variable.

The analysis of completeness over the years showed that the set of notification variables supported good/excellent completeness during the period, whereas the monitoring group showed worsening in completeness over the years, going from excellent (4.7%) in year 2008 to regular (14.5%) in 2017.

The filling in of the group of the complementary variables reached a poor grade (21.7%) in 2014, evolving with more satisfactory ratings over time (Figure 2).





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FIGURE 2: Incompleteness percentage of the tuberculosis variables of the Information System for Notifiable Diseases of the state of Paraná, according to the groups of variables. Paraná, Brazil, 2008-2017.

DISCUSSION

The quality of health data is an important attribute for providing an understanding of the behavior of diseases in a given geographic space, in addition to assisting in the planning, implementation and evaluation of health actions^{19,10}.

During the period evaluated, the state of Paraná showed regular general completeness for tuberculosis according to the SINAN database. It should be noted that the lack of adequate filling in of the variables can be related to the lack of involvement of the professionals responsible for the notification, to ignorance about the importance of the information to be collected, conceiving such activity as a mere bureaucratic assignment, without connection to the quality of the service²⁰; to ignorance of the information flow in the¹⁹ system or to overload of the health professionals who channel their time into activities considered as priority according to their judgments⁵.

The SINAN data generated in the municipalities must be transferred weekly by the municipal health secretariats to the state secretariats, which must send the state data to the Health Surveillance Secretariat (*Secretaria de Vigilância em Saúde*, SVS/MoH) every two weeks, with each federal unit being responsible for the quality of the data transmitted¹⁶. In the searches performed in the literature, no program that includes the quality control of SIS data was found at the state level or in the municipalities of the state of Paraná.

It is the responsibility of the Union, the states and municipalities, to value the quality of the health databases, each of them having a set of attributions and responsibilities¹⁶. For the continuous process of data quality control, it appears coherent to verify the completeness of the data at regular intervals, the dispatch of technical monitoring reports, training of health professionals, continuing technical visits of an educational nature to strengthen the bond and co-responsibility between administrative levels aiming at the management, structuring and operationalization of the SINAN.

The completeness classified as excellent for the mandatory variables was already expected because the lack of this data makes it impossible to insert the notification in the SINAN. There was a variation from excellent to very poor in the essential variables, which are those that do not have to be filled in, although they are important for the calculation of epidemiological and operational indicators¹⁶, as is the case of the ST, smoking and illicit drugs.

The universal offer of the ST is a component of the prevention and patient-centered care pillar in the National Plan for the End of TB, which, based on the model proposed by the WHO, aims to reduce the incidence of the disease to less than 10 cases per 100,000 inhabitants and the mortality coefficient to less than 1 death per 100,000 inhabitants by the year 2035²¹. The impairment of the ST offer leads to a delay in the diagnosis of cases that are resistant and the use of an ineffective treatment scheme²². A previous study²² pointed out that the median time between confirmation of tuberculosis diagnosis and detection of resistance was 12 months, which contributes to the maintenance of the transmission chain of the resistant bacillus and to the worsening of the clinical conditions of the patient.

Indicators of social vulnerability, including the use of licit or illicit drugs, hinder the creation of a satisfactory bond with the health service and are predictors of greater risks of treatment abandonment^{23,24}, which turns the low completeness of data for these variables into a concern. Smokers have a 70% greater chance of a negative outcome in



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the treatment of tuberculosis when compared to those who do not smoke²⁵. In addition, smoking is associated with delay in the diagnosis of the disease²⁶, treatment failure²⁷, relapse and greater chances of death^{28,29}, reinforcing the importance of the correct registration of data in the SIS.

Regarding the classification of variables by group, the notification one was the only that maintained good/excellent completeness during the period evaluated, possibly because it encompasses a higher percentage of mandatory variables. Satisfactory completion in this group is important because variables such as race, gender and schooling contribute to the identification of individuals who are more likely to have negative outcomes, given that they are predictive factors associated with treatment failure, abandonment and death^{13,30}. In this group of variables, the improvement in filling in information about the schooling of the individuals over time can allow for the provision of adequate care to them, since, depending on education, the understanding of the health-disease process is different, as well as the ability to understand and follow the guidelines on the disease and treatment³¹.

Although the monitoring group had a mean completeness classified as good for the period studied, this group went from excellent completeness in the initial years of the study, going through completeness classified as good and to regular in the final years and, if this pattern continues, in the future there may be a negative impact on the positive outcomes of the cases of the disease.

The regular classification of completeness in the variables of the monitoring group from the year 2014 on can indicate carelessness in filling out the information system because these variables are not mandatory, as well as unsatisfactory monitoring of the cases, especially with respect to the performance of the control sputum smear baciloscopy, whose filling has worsened over time. Also in the monitoring group, a weakness can also be assumed in the bond between the individual and the health service, which has great potential to be provided by the DOTS³². The bond created between the patient and the health service is of great importance for the continuation of tuberculosis treatment, as close bonds and good communication allow the individuals to feel more secure in explaining their doubts and desires³¹. Well-established communication between the individual and the health professionals is essential to avoid treatment abandonment.

A previous study³² showed that individuals with insufficient monitoring performed by the health services were more strongly associated with abandonment, complications and death. The loss of monitoring of the patients can increase the rates of notification and cases of recurrent tuberculosis and prolonged infection, increase cases of resistance, as well as increase the rates of disease morbidity and mortality³³.

Patients with a history of abandoning treatment have social determinants that increase the chances of this choice being repeated, requiring health professionals to perform a robust monitoring of patients with the disease, adapting the treatment to their reality, in order to minimize the risk of negative outcomes³⁴.

The change in the tuberculosis notification form in the year 2014 may have impacted on the completeness of the variables of the complementary group in that year, since their registration had been indicating improvements over time even with this group presenting three quarters of essential variables. The modification resulted in the removal of the following variables: occupation, institutionalized individual, tuberculin skin test, sputum smear microscopy and culture of material other than sputum, drugs used in treatment, indication for DOTS and whether the disease was work-related and the inclusion of the following variables: post-obitus in the type of individual entering the system, special populations, government beneficiaries, use of illicit drugs and smoking in the field associated diseases and conditions, use of antiretroviral therapy during treatment, result of the rapid molecular test for tuberculosis (RMT-TB) and result of the ST.

The modification in the disease notification form covered part of the constituent variables of the complementary group that presented worse data completeness in the year 2014, probably related to the implementation and adaptation with the new form in the health services and to the transition period from the old form to the current one. In addition, in that year it was possible to observe a high proportion of incompleteness in the institutionalized variable (last year of the variable in the system) and sensitivity test (new variable), as well as in the data on drug – 42.3% and tobacco – 43.6% use (data not shown). It is believed that the registration of the sensitivity test is not done due to not all patients performing the same test, as well as to the fact that the result is time consuming, leading the professionals to forget to record such information³⁵. As for filling in data on the use of psychoactive substances, they can also help in the design of the treatment of TB patients, in such a way that the health professionals who work in the care of the disease need to dialog with the psychiatric services, for harm reduction and even with social work for comprehensive care for these individuals, given the difficulties faced to promote adherence to treatment for this group of patients²³.

Also in the group of complementary variables, it is possible to observe an improvement in the registration of AIDS information over time, raising the hypothesis that such improvement accompanies the process of demystifying the



disease over time or greater awareness of the health professionals regarding the importance of carrying out this type of registration for the adequate definition of drug treatment.

Study limitations

It is important to consider the following limitations of the study: type of study, which does not allow for considerations about specific municipalities of the state; a possible bias of information for using secondary data; an overview of the completeness of the Tuberculosis Information System in the state of Paraná was chosen, grouping mandatory and essential variables, which can be questioned methodologically (although the presence of these variables in the groups has been duly considered in this discussion).

CONCLUSION

The unsatisfactory completeness identified in the SINAN database regarding tuberculosis in the state of Paraná can lead to unreliable data on the epidemiological profile of the disease and cause difficulties in its use as a tool for the formulation of public health policies and for the evaluation of actions implemented for the prevention and control of the disease.

The importance of states and municipalities having a data quality control program in the SIS and the continuous training of health workers related to the relevance of properly filling out the system fields is emphasized, which translates not as a mere bureaucratic assignment devoid of care, but as an enhancer of a valuable tool for planning public health policies.

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