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Unnotified deaths and hospital admissions for tuberculosis in the municipality of Rio de Janeiro

ABSTRACT

OBJECTIVE: To analyze underreporting of deaths and hospital admissions from tuberculosis to the Information System for Notifiable Diseases (SINAN).

METHODS: Cases with tuberculosis as basic or associated cause of death were selected from the Brazilian Mortality Information System (SIM) and hospital admissions for tuberculosis as main or secondary cause from the Hospital Information System of the Brazilian Unified Health System (SIH-SUS), for residents in the municipality of Rio de Janeiro in 2004. Probabilistic record linkage was carried out between the SIM and SIH-SUS databases and the SINAN for the years 2002 to 2004.

RESULTS: Out of the 542 deaths from tuberculosis in the period, 234 (43.2%) were not registered in the SINAN for the two previous years. As for the 1,079 admissions, 238 (22.1%) failed to be notified. Seventy-one deaths were related to these admissions: 47 were registered out of the SIH-SUS by death, 24 occurred after discharge and seven remained unnotified in the SINAN. The elderly were 1.6 times (95%CI 1.074;2.516) less likely to be notified than younger patients, and those with at least a college education were 3.6 times (95%CI 1.384;11.022) less likely to be notified than those with no formal education. Patients under 15 were 4.8 times (95%CI 2.757;8.452) less likely to be notified than those aged between 15 and 59 years. Some regional health administration divisions showed a percentage of unnotified deaths of over 50% and this percentage ranged from 37.8% to 12.7% for hospital admissions.

CONCLUSIONS: The data suggest problems in the detection of cases and point to obstacles in adequate and timely treatment, as well as to quality flaws in the information system, with differences among regions in the municipality.

DESCRIPTORS: Tuberculosis, epidemiology. Tuberculosis, mortality. Disease Notification. Underregistration. Registries. Hospital Information Systems. Mortality Registries.

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INTRODUCTION

The Brazilian government recognizes tuberculosis (TB) as a serious public health problem. The National Tuberculosis Control Program (NTCP), initiated by the Ministry of Health in 1999, defines the fight against TB as a priority among government health policies and establishes guidelines for reaching this aim.^a The World Health Organization (WHO) sets as international goals, agreed upon by

^a Ministério da Saúde. Fundação Nacional de Saúde. Tuberculose: guia de vigilância epidemiológica. Brasília, DF; 2002.

the Brazilian government, the capture of 70% of estimated TB cases, cure rate of 85%, and default treatment abandon rates of up to 5%.^b The municipality of Rio de Janeiro, Southeastern Brazil, had an incidence rate of 103.7 cases per 100,000 population in 2005,^c above the national average (43.8 per 100,000 in the same year),^d foreclosure of 72.2% of cases with cure and a 13.8% abandon rate,^c 2.76 times higher than the target agreed upon by the government together with the WHO.

For TB control actions to be effective, the NTCP dictates that those actions should be decentralized and that TB control and primary care should be integrated to ensure increased access to diagnosis and treatment. This integration must include the model of the Community Health Agents Program (CHAP) and the Family Health Program (FHP).^b In the municipality of Rio de Janeiro, persons diagnosed with TB are referred to their nearer Tuberculosis Control Program (TCP), and are followed at health centers and clinics. Treatment is initiated by notification to the Information System for Notifiable Diseases (SINAN).

SINAN is a universal, nationwide epidemiological surveillance tool that assists and supports decision making. Besides SINAN, there are other databases that record events related to TB in Brazil, such as the Mortality Information System (SIM) and the one related to production of hospital services (Hospital Information System of the Unified Health System, SIH-SUS), whose data are made available by the Ministry of Health/Datasus.

Analysis of these data allows the creation a TB profile in the country and the monitoring of the individual in different situations of disease through a comparison between the systems. It can also provide additional analysis on surveillance of cases and patient care. Outcomes hospitalization or death can be used as parameters to assess the severity of the endemics, delay in case detection, delay in treatment onset and its effectiveness. Deaths or hospitalizations for TB not notified in the SINAN may suggest obstacles in the access to health services and quality flaws in the system, since the diagnosis was probably given to the individual in an extreme situation, ie, without prior identification of the disease by the basic health services or referral to outpatient treatment. This first contact with a health service can be filled with obstacles and barriers to be overcome, related to the characteristics of the population or their power to overcome these obstacles.^{4,6}

Therefore, this study aimed to analyze the underreporting of hospital admissions and deaths from TB in SINAN.

METHODS

All death cases among residents in the municipality of Rio de Janeiro in 2004 and which showed tuberculosis (A15 - A19) as main or associated cause of death, according to the International Classification of Diseases, 10th Revision (ICD-10), and as registered in SIM were selected. The admissions in 2004 whose diagnosis included tuberculosis in one of its fields (primary or secondary) were selected in the SIH-SUS. These data were linked to the SINAN database from 2002 to 2004. Unnotified cases in this period were considered as having limited access to health services. Access is understood not only from a geographic point of view or by the care administered after seeking out the health unit, but also the individual's perception of the health services, the need to access them and to continue receiving treatment.¹²

There is no common identifier for all databases in the study so the records were linked probabilistically with the Reclink III software.¹ SIM was linked with SINAN and SIH with SINAN separately, in five steps, as described by the blocking strategy suggested by Coeli and Camargo.² Variables name, date of birth, mother's name and address were used for linkage with SIM. Variables name, date of birth and address were used to compare the records between the bases for the linkage with SIH-SUS.

In case of multiple hospital admissions or notifications, only one record of each person was selected for the same individual. The record was chosen based on the date of TB treatment completion filled in according to duration of treatment. When the field was not filled in, the most recent date of notification was checked. If no notification was made, the most complete record was selected, with fewer blank fields, and with better quality of data.

In addition to the linkage of the bases with SINAN, another was carried out between the SIM and SIH-SUS bases so as to avoid double-counting of individuals recorded on admission and who died of TB. The following variables were used: name, date of birth and address.

The crude and adjusted odds ratio (OR) were calculated for individuals who died of TB and were not notified in the SINAN using logistic regression (simple and

^b Ministério da Saúde. Secretaria de Gestão Participativa. Reorganizando o SUS no Município do Rio de Janeiro [Internet]. Brasília, DF; 2005[Cited 2007 Aug 25]. Available from: http://dtr2001.saude.gov.br/editora/produtos/livros/pdf/05_0421_M.pdf

^c Secretaria Municipal de Saúde do Rio de Janeiro. Coordenação de Doenças Transmissíveis. Boletim Informativo do Programa de Controle da Tuberculose do Município do Rio de Janeiro: situação epidemiológica da tuberculose 2001 a 2006 [Internet]. Rio de Janeiro; 2008[Cited 2009 Mar 17]. Available from: http://www.saude.rio.rj.gov.br/media/BoletimEpidemiologicoTBM RJ2001_2006.pdf

^d Ministério da Saúde. Departamento de Informática do SUS. Informações de saúde: indicadores de morbidade e fatores de risco 2005 Brasília, DF;2007[Cited 2009 Mar 19]. Available from: <http://tabnet.datasus.gov.br/cgi/idx2007/matriz.htm#morb>.

multiple models, respectively), according to socio-demographic characteristics. The same was done for admissions. Due to the few death cases among children under 15, these cases were grouped with those aged 15 to 59 years in order to calculate the OR for unnotified deaths from TB.

The district of residence was obtained using the street address on the post office website.^c The districts were grouped according to the regional health division of Rio de Janeiro, known as a Program Area (PA). The division consists of ten areas of sanitary planning, so devised to facilitate the regionalization of health actions and services in the municipality. The percentage of unnotified deaths and admissions for tuberculosis was represented on maps.

The exploratory analysis were performed with EpiInfo 6.04. The OR of unnotified subjects was calculated with the aid of Stata 9.0 and the maps of the distribution of the unnotified cases by program areas were developed with the aid of Tabwin 3.5.

The network of program areas in the municipality of Rio de Janeiro was provided by the Laboratório de Geoprocessamento do Instituto de Comunicação e Informação Científica e Tecnológica em Saúde (ICICT/Fiocruz). Data were provided by the Rio de Janeiro State Department of Health and Civil Defense.

The project was approved by the Ethics in Research Committee of the Instituto de Estudos em Saúde Coletiva (Process number 67/2006).

RESULTS

In 2004, there were 542 death certificates with TB as main or associated cause in the municipality of Rio de Janeiro. Of these, 389 (71.8%) had TB as the main cause whereas 109 (20.1%) had AIDS as the main cause (Table 1). More men (73.1%) had the disease than women (26.9%), and the most frequent age group is 15 to 59 years (70.5%), followed by 60 years or more (28.4%). Two cases were under 15 years. Persons with four to seven years of formal education (elementary or high school) were more frequent (32.7%).

Of the 1,079 admissions with TB in one of the fields of diagnosis, 978 (90.6%) had tuberculosis as a main reason for hospitalization and 63 (5.8%) had AIDS. Similarly to the deaths, more men (74.4%) had hospital admission by the disease than women (25.6%) and the most frequent age group was 15 to 59 years (82.8%), higher than that observed for the deaths.

Of the deaths, 234 (43.2%) were not recorded from 2002 to 2004 in SINAN, while 238 admissions (22.1%) were not notified in the same period.

Table 1. Characteristics of individuals who died or were hospitalized for or with tuberculosis. Municipality of Rio de Janeiro, Southeastern Brazil, 2004.

Variable	n	%
Deaths		
Sex		
Male	396	73.1
Female	146	26.9
Age (years)		
Less than 15	2	0.4
15-59	382	70.5
60 or more	154	28.4
No Information	4	0.7
Formal education (complete years)		
None	36	6.6
1 to 3	137	25.3
4 to 7	177	32.7
8 to 11	70	12.9
12 or more	29	5.4
No Information	93	17.2
Total	542	100.0
Hospital Admissions		
Sex		
Male	803	74.4
Female	276	25.6
Age (years)		
Less than 15	57	5.3
15-59	893	82.8
60 or more	129	12.0
Total	1.079	100.0

Sources: Mortality Information System and Hospital Information System of the Unified Health System

Men were more likely not to be reported in SINAN compared to women (OR = 1.213, 95%CI 0.935; 2.191), but with no statistical significance (Table 2). The elderly were 1.6 times (95%CI 1.074;2.516) more likely of not being reported compared to younger patients.

College level education or more showed 3.6 times (95%CI 1.384;11.022) greater chance of not being reported than no formal education, and primary or middle education meant 2.1 times (95%CI 0.9;4.6) less likelihood, but with no statistical significance. The likelihood of children under 15 not being reported was 4.8 times (95%CI 2.757;8.452) higher than those aged between 15 and 59 years. Persons over 60 years (OR = 1.5, 95%CI 1.074;2.369) are also less likely to be reported (Table 2).

^c Empresa Brasileira de Correios e Telégrafos [Internet]. [Cited 2009 Mar 19]. Available from: <http://www.buscapep.correios.com.br/>

Table 2. Odds ratio of unnotified deaths and hospitalizations due to TB in the period 2002 to 2004, according to characteristics of the individual. Municipality of Rio de Janeiro, Southeastern Brazil, 2004.

Variable	Total	unnotified (%)	crude OR	95%CI	adjusted OR	95%CI
Deaths						
Sex						
Male	396	44.4	1.213	0.824;1.786	1.431	0.935;2.191
Female	146	39.7	1	-	1	-
Age (years)						
Up to 59	384	39.8	1	-	1	-
60 or more	154	51.9	1.632	1.120;2.378	1.644	1.074;2.516
Formal education						
None	36	27.8	1	-	1	-
Primary or secondary school	384	45.0	2.131	1.000;4.542	2.149	0.999;4.622
College or more	29	58.6	3.683	1.304;10.402	3.854	1.384;11.022
Total	542	43.2				
Hospital Admissions						
Sex						
Male	803	21.0	0.799	0.580;1.102	0.887	0.637;1.235
Female	276	25.0	1	-	1	-
Age (years)						
Less than 15	54	53.7	4.827	2.757;8.452	4.714	2.682;8.285
15-59	893	19.4	1	-	1	-
60 or more	132	27.3	1.560	1.028;2.369	1.548	1.019;2.352
Total	1079	22.1				

Of the 542 deaths and 1,079 hospitalizations, 71 (13.1% of deaths and 6.6% of admissions) were cases of hospitalization followed by death (Figure 1). Of these, 64 (90.1%) were notified and seven (9.9%) were not. Four of these admissions were made in hospitals with emergency services. Furthermore, 47 (66.2%) had death as hospital record output, and 24 (33.8%) occurred after discharge from hospital with a diagnosis of TB.

The percentage of unnotified cases varied among the different areas in the city (Figure 2). In some areas of planning, values were around 56%, while in others, 25% for deaths and 37% and 12% for hospitalizations.

The foreclosure situation was not filled in for 130 (42.2%) deaths cases notified.

DISCUSSION

Unnotified deaths and hospital admissions for TB represents a major health problem in Rio de Janeiro. It was observed that 43.2% of deaths and 22.1% of admissions were not notified to SINAN during the study period, i.e., 467 persons identified with TB in hospital admissions in the SUS network or who died of TB were not in the SINAN records, an increase of 5.4% in notification. To estimate the incidence rate,

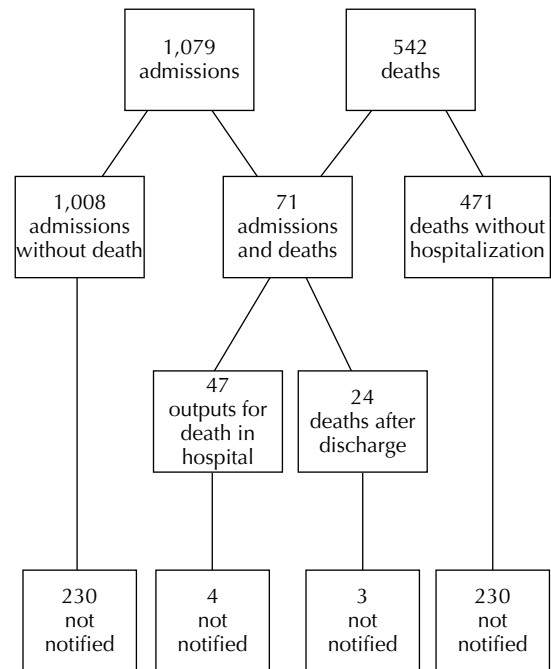


Figure 1. Diagram of the distribution deaths from TB, hospitalizations and matching records in databases Mortality Information System and Hospital Information System of the Unified Health System. Municipality of Rio de Janeiro, Southeastern Brazil, 2004.

considering the unnotified cases to new cases notified in 2004, and assuming they have not been notified in the period preceding the study, the incidence rate would increase from 108.5 to 116.4 cases per 100,000 population, a 7.2% increase.

The percentage of unnotified cases observed may be due to flaws in the quality of the information system. The cases may not have been entered into the SINAN, but nonetheless received treatment at health units. Although not representing a high percentage of the total cases, these were patients with severe outcomes, whose characteristics were not reported in the main

surveillance database. There may be underreporting in the Sinan if the same percentage of unnotified deaths and hospitalizations is applied to notified cases, assuming that typos in SINAN could be randomly distributed.

Moreover, individuals may not have received treatment before hospitalization or death from TB, which characterizes a barrier in access to timely and adequate treatment, according to a wider concept of access.¹² This hypothesis is supported by the results observed by Selig et al,¹¹ who identified problems in TB care and diagnosis by investigating deaths in hospitals in the city.

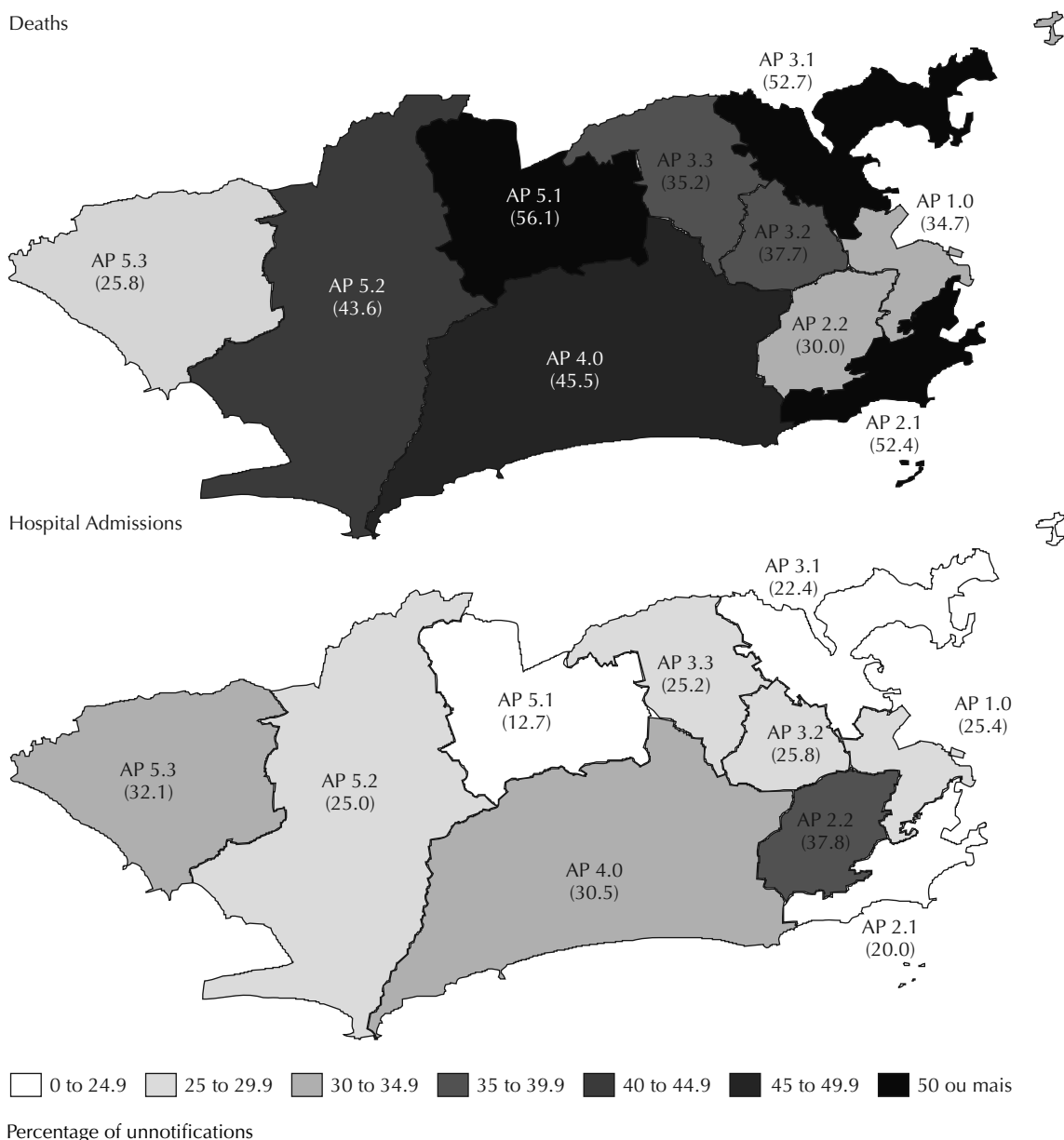


Figure 2. Percentage of unnotified deaths and hospitalizations for TB in the period 2002-2004, according to planning areas. Municipality of Rio de Janeiro, Southeastern Brazil, 2004.

The retrospective following of TB cases in SINAN that progressed to death or hospitalization was shorter than the five years recommended by the NTPC for an individual registered in the information system to be considered a new case of TB.⁸ However, the monitoring a period of two years indicates a major gap in the treatment of individuals with TB, pointing to possible barriers in the access to health services, with detection problems for the NTPC and/or flaws in the information record. Façanha³ showed that 66% of the deaths were not notified in the year in which they occurred for the period of 1999 to 2002 in Fortaleza, Northeastern Brazil. Follow-up time was shorter than in the present study and may have excluded those previously reported, indicating the importance of the results found here.

Elderly individuals who died or were hospitalized with or because of TB were less likely to be reported younger adults. Access to health services has been seen as inversely associated with age.^{5,7} This reinforces our hypothesis that older patients have difficulty accessing the TCP, as represented by the large number of unnotified cases. In the case of hospital admissions, children were more likely not to be reported than adults, which could indicate that the diagnosis was inadequately recorded in the SIH/SUS, or that these children died, and so were reported in the SIM. A follow-up of the individuals starting in 2004 would check this hypothesis.

The likelihood of not being reported when the individual had college education or more was significantly higher (almost four times) than that of those without formal education. The fact that patients with better social status have a higher proportion of the disease or do not receive timely and adequate treatment may be due to observational bias, since TB is commonly associated with poverty.⁸ On the other hand, more educated individuals may have more access to health services and diagnosis, at least in death, than those with fewer years of education, which could explain this result.

The program area divisions in Rio de Janeiro were used as units of analysis in this work since these divisions should inform changing sanitary practices based on territory and constitute a Sanitary District. According to the design proposed in the VIII National Health Conference, this would be an attempt to facilitate regionalization of health services and actions. The Health District is the smallest territorial unit with the autonomy to define, plan, organize, manage and implement health actions aimed at the population of that territory.^f Still, the program areas differ from each other with greater variation between deaths and hospital admissions in areas PA 5.1 and 2.1. Both regions had highest number of unnotified deaths

and the highest number of notified admissions. These two regions have different characteristics. PA 2.1 is represented by Botafogo, Copacabana and Lagoa and is considered to have living good conditions and high life expectancy. It also has a considerable elderly population, i.e., individuals seen as more likely to develop the disease.¹³ PA 5.1 houses the Bangu Penitentiary, with a population historically excluded from public policy. The hypothesis of observation bias and better diagnostic capabilities gains strength in the PA 2.1, while in PA 5.1 the most likely explanation is the poor quality of case records or low timely uptake.

Although the picture for hospital admissions seems better compared to the deaths, hospital admissions are computed only within the SUS, while the SIM also includes deaths occurring outside the Unified Health System.

This study allows an analysis of questions related to access and notification of TB cases in Rio de Janeiro. Although the study design cannot determine the causes, some hypotheses can be formed. Possible explanations are related to characteristics of the individuals and services. The lack of awareness about the disease and its severity, the precarious conditions of life and comorbidities, such as alcoholism, hardly explain the entire problem. A portion can be explained by deficiencies in diagnosis,⁹ a hypothesis reinforced by the results of Selig et al. in the state of Rio de Janeiro in 1998,¹⁰ which showed that unnotified deaths from tuberculosis were associated with a poorer diagnosis. Health services can be used strategically to reduce this picture and part of the NPTC is based in the availability of services.

To meet the challenge of controlling TB in Brazil, the Family Health Strategy (ESF) is recognized as a gateway to expand access to health services,^b with positive results regarding disease control.⁸ However, the Family Health population coverage in Rio de Janeiro, January 2009, was of 6.9%,^g which compromises its use as a strong strategy and delegates to the primary health care alternatives for broader action.

In cases of doubt regarding two records belonging to the same individual, these were considered a pair for linkage, differently to passive follow-up studies of survival. To consider a true pair meant that the individual had been reported; disregarding the pair, on the other hand, could increase unnotified cases, which would in turn increase the sensitivity of the method.

It was expected that all or most of the deaths and hospitalizations from TB would be notified at least on the day of the event, but the record of many individuals were not

^f Ministério da Saúde. Secretaria de Gestão Participativa. Reorganizando o SUS no Município do Rio de Janeiro 2005. Brasília, DF; 2005 [Cited 2007 Aug 25]. Available from: http://portal.saude.gov.br/.../reorganizando_SUS_municipio_rio_de_janeiro

^g Ministério da Saúde. Departamento de Atenção Básica. Histórico de cobertura de saúde da família [Internet]. Brasília, DF; sd. [Cited 2009 Mar 21]. Available from: <http://200.214.130.35/dab/>

included in the notification system even after the disease was identified. Notification may have occurred the year after death or hospitalization, which would produce an overestimation of unnotified events. On the other hand, events reported after their occurrence may underestimate obstacles in access to health services because they are not counted as unnotified. Thus, it is possible that the percentage of deaths and hospitalizations not reported exceeds the 43.2% and 22.1% identified, respectively. SINAN is a powerful tool for epidemiological surveillance and can help support decision taking, but unnotified cases affect the representation of the real epidemiology profile of the disease. Likewise, poor data due to blank fields, inconsistency of information and duplication of records may affect the use of this tool.^h The foreclosure situation, an important field important for the TCP assessment, was not completed for notified deaths in 42.2% of cases, indicating flaws in the quality of these data. A study conducted to investigate the deaths attributed to TB in Rio de Janeiro,¹⁰ revealed that after a review of notified data, the number of cases increased from 16,001 to 17,351 (an 8.4% increase).

Quality of data is crucial for the use of any information system as a tool for dynamic diagnosis of a population's health situation. Identifying the epidemiological reality of a given geographical area may provide a basis for causal explanations of a disease and

indicate potential risks to which people are subject,ⁱ which allows for fast and efficient actions by workers and health managers.

The linkage of databases allowed the identification of unnotified cases of deaths and hospitalizations in Rio de Janeiro. Although a relatively simple task, the integration of databases is limited in services. Information retrieval for SINAN from the SIM and SIH-SUS may represent an important activity for improving the quality of this information system and can be incorporated as routine at the local level. The use of probabilistic linkage software allowed us to map the concentration of underreporting of cases, in addition to outlining the profile of these individuals based on data from death certificates and from the Authorization for Hospital Admission. It is possible to incorporate the technique of database linkage in order to draw a more accurate epidemiological profile. This technique can be routinely adopted by managers in the use of information. The high number of deaths and hospitalizations without notification may point to low uptake of cases or failures of notification by the program.

Besides enabling the design of a better epidemiological profile, the return of information to various levels of usage reinforces the constant process of improvement of data and of the information system itself.

^h Ministério da Saúde. Secretaria de Vigilância em Saúde. Programa Nacional de Controle da Tuberculose. Brasília, DF; 2004.

ⁱ Ministério da Saúde. Secretaria de Vigilância em Saúde, Departamento de Vigilância Epidemiológica. Sistema de Informação de Agravos de Notificação - Sinan: normas e rotinas. Ministério da Saúde 2006 [Cited 2009 Oct 14]. Available from: http://dtr2001.saude.gov.br/editora/ produtos/livros/popup/07_0098.htm<http://dtr2001.saude.gov.br/editora/ produtos/livros/popup/07_0098.htm>

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