Original Article

Underreporting of tuberculosis cases from death surveillance*

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ABSTRACT

The objective was to analyze underreporting of tuberculosis cases from the capture of deaths registered at the Mortality Information System (SIM) from 2007 to 2011. We conducted a retrospective study in a city at the Northeast region of Brazil using a non-probabilistic association technique between SIM registries and the Information System on Diseases of Compulsory Declaration (Sinan), through the software Reclink III. We calculated odds ratios (OR) of individuals who died from tuberculosis not reported at Sinan, according sociodemographic characteristics. From 147 deaths registered at SIM, 72.8% were not notified at Sinan. Women were more likely to not be reported than men (OR = 2.60), people younger than 60 years (OR = 1.86), with less than eight years of education (OR = 4.42). Strategies should be re-signified in a way to capture more respiratory symptoms, to opportunely diagnose cases and to avoid flaws when completing registries.

Descriptors: Tuberculosis; Health Information Systems; Disease Notification.

INTRODUCTION

Globally, persistence of tuberculosis (TB) is a reflex of iniquity – social and economic inequalities, causing an important impact in morbidity and mortality, especially among the most vulnerable segments of population.

In 2014, 9.6 million of new tuberculosis cases were notified in the world, 12% (1.2 million) were seropositive for HIV. At the same period, there were 1.5 deaths from tuberculosis and 400.000 of those were

co-infected people (TB/HIV). A total of 80% of cases are concentrated in 22 poor and emergent countries, with special incidence in the Sub-Saharan Africa, where four out of five tuberculosis cases are registered[1].

According to estimates from the World Health Organization (WHO), in 2014, Brazil registered the incidence of 44 new cases per 100.000 inhabitants and a mortality rate of 2.6 deaths per 100.000 inhabitants. Although a reduction of incidence and mortality coefficients on the last decade is observed, the country concentrates 35% of notified cases in the American regions[1] and still, it has not reached the goal stipulated by the WHO to detect at least 90% of tuberculosis cases[2]. The difficulty of health services to capture new cases, diagnostic errors, late diagnosis, absence of search for cases in different registry sources, delays to notify and, the information processing are questioned[3-4].

Within the strategies to reach the agreed global goals, it is necessary to systematically integrate a group of vigilance actions to identify points of strangulation between the capture process and the notification of new disease cases[3].

Health information should serve to reduce uncertainties and to identify priority situations in order to subsidize an adequate planning to execute actions conditioning reality to the needed transformations. Health Information Systems (SIS) congregate many subsystems; it components allow collection, processing, analysis and transmission of necessary information to plan, organize, operate and assess health services[5]. They are true support devices for the decision making process.

However, availability of systems and informatics resources are not enough if not adequately comprehended and operated. Advances from scientific and technological knowledge and better understanding about the health-disease process and its determinants broadened the public health' focus of analysis. On the other hand, the ability to measure population health state and, efficacy of services and effects were expanded; those are processed by the use of indicators of morbidity, mortality, and coverage, access to services, quality of attention, life conditions and environmental factors, within others. Evidently, the quality of the produced data is essential so that health indicators can meet is purposes with satisfaction[6].

For tuberculosis control, the data generated by the Information System on Diseases of Compulsory Declaration (Sinan) subsidizes the opportune triggering of interventions, monitoring and processes' evaluation[7]. It englobes notification and accompaniment of cases, gathering quantitative and qualitative information that constitutes a basis to calculate epidemiological and operational indicators[8]. Thus, its utility is measured by the quality of data, precision and completeness of information.

Additionally, epidemiological information can be obtained from other health information systems as the Mortality Information System (SIM). The analysis of SIM and Sinan databases allows to identify the epidemiological profile of TB cases and to accompany individuals in different disease situations through linkage[9] of systems, allowing complementary analyses of vigilance and attention of cases. The occurrence of non-notified cases at Sinan can suggest access barriers to health services and flaws in the system's quality, once probably, the diagnosis was given to an individual in an extreme situation – death, for example, without being previously diagnosed by the health attention network, especially by the primary health care[10-12].

Acknowledging that underreporting of tuberculosis cases from death surveillance is an important marker to assess the disease severity, delay in diagnosis and opportune treatment, this study aimed to analyze the underreporting of tuberculosis cases from the capture of deaths registered in the Mortality Information System from 2007 to 2011.

METHODS

We conducted a retrospective study, in which the population was constituted by all deaths presenting TB as basic cause, independently of the clinical form (International Classification of Diseases – ICS version 10 codes A15.0 and A19), registered at the Mortality Information System (SIM) from 2007 to 2011, residing at a Brazilian northeast capital. It still aggregated data from the Information System on Diseases of Compulsory Declaration (Sinan) with the purpose to identify underreported cases.

We chose the investigation period based on the introduction of the Sinan Net version in 2007, and on the opportune ending of tuberculosis cases until 2011. To also increase the specificity of registries, we also analyzed Sinan data from 2005 and 2006.

The databases were provided by the Management of Education in Health from the city of João Pessoa – Paraíba, and processed on September of 2013.

We conducted the study in two steps: linking Sinan registries (systematic routine of this system) to treat duplications; and linking Sinan to SIM, to identify underreporting of tuberculosis from SIM.

We used the tabwin software version 3.6b to link and/or exclude Sinan registries. The linkage occurred when there were double registries (a case notified more than once by the same or another health unit, during the same treatment). In these cases, we kept the first notified registry and/or we complemented data from the 1st notification with data from the 2nd notification and, later, we excluded the 2nd notification.

We excluded true duplications (the same patient was notified during the same treatment more than once by the same health unit). The exclusion occurred when there were two or more notifications of the same patient, during the same treatment and, with the same ending.

To investigate and quantify cases non-detected or ignored by Sinan-TB, we used the probabilistic linkage method of registries, through the software RecLink III. This method consists on identifying the common field for Sinan-TB and SIM, to check how likely is that a pair of registry refers to the same individual[(9)].

In the linkage between SIM and Sinan-TB, we did a five blockage steps with a combination of fields. It started with a more restricted key and with posterior decrease of restriction to minimize losses of pairs, that is, the occurrence of a false negative:

- *Soundex* (first name) + *soundex* (last name) + gender;
- *Soundex* (first name) + *soundex* (last name);
- *Soundex* (first name) + gender;
- *Soundex* (last name) + gender;

In the fifth blockage step, we repeated the combination of the first step with a lower score value, increasing the sensitivity to find new pairs. In all steps, we used name fields for patients, mother's name and, date of birth to compare and calculate scores. One unique researcher conducted a manual review of doubtful pairs at the end of each step, following criteria for tiebreaking: patient's name, mother's name, date of birth and, city of residence.

We opted to consider the paired registration that remained doubtful after the manual review process to minimize occurrence of false-negative errors. Thus, observed results can be interpreted as a conservative estimate of TB notification cases.

We considered scores higher than 22.4 as true pairs while those lower than 9.7 were considered not paired. We considered doubtful ones as intermediate pairs. We opted to consider those doubtful pairs after manual review process, as a pair, to minimize mistakes (false negatives). Thus, observed results can be interpreted as a conservative estimate of TB notification cases.

During this process, death registries were associated with more than one notification from the same individual at Sinan-TB because they were duplicate registries, relapse cases, or a restart after withdrawing treatment. With the intention to eliminate repetitions of the same case, we excluded notifications with older diagnostic data from analysis.

We recalculated TB incidence rates of the city, adding cases not notified at Sinan but recovered at the SIM database, excluding coincident cases between bases. We used the population estimate from 2007 to 2011.

We calculated raw odds ratio for individuals who died of non-notified tuberculosis at Sinan, according to sociodemographic characteristics and, we built their respective confidence intervals –CI for a 5% level of significance, using the Wolf method. We used the Chi-Squared association test to verify statistical significance.

The study was submitted to the Ethics in Research Committee from the University Hospital Lauro Wanderley from the Universidade Federal da Paraíba, approved in August 27th , 2013 under the protocol n° 377.615.

RESULTS

During 2007 to 2011, 2,184 tuberculosis cases were notified on Sinan-TB. From those, 396 notifications were in 2007, 446 notifications in 2008, 491 notifications in 2009, 416 notifications in 2010 and, 435 notifications in 2011. During this period, 147 deaths from tuberculosis were registered on SIM. When linking the two databases, 107 deaths from tuberculosis were not present on Sinan-TB, presenting a 72.8% of underreporting of cases (Figure 1).

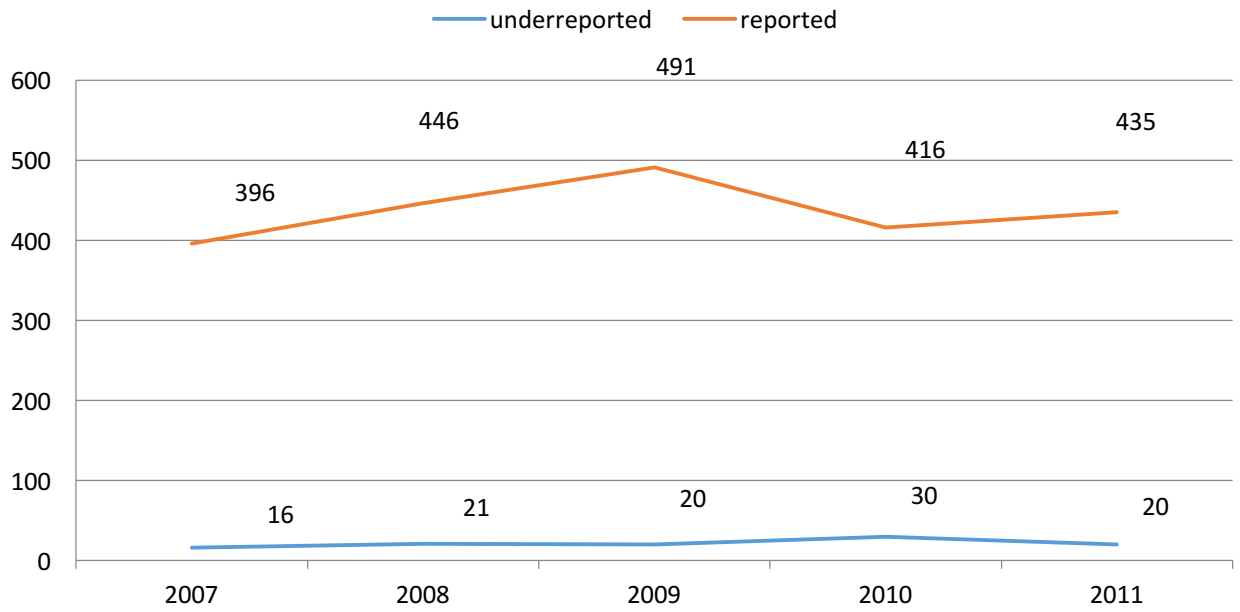

Figure 1: Reported cases of tuberculosis on Sinan and underreporting identified from SIM. João Pessoa, PB, Brazil, 2007 to 2011.

In 2007, 22 deaths from tuberculosis were registered on SIM, being 16 (72.7%) underreported on Sinan, in 2008, 21 underreporting (77.7%), in 2009, 20 underreporting (74.1%), in 2010, 30 underreporting (77.0%) and in 2011, 20 underreporting (64.5%).

During the studied period, we observed an E(x) (expected value) of 21.4 (95% CI = 16.26-26.54) annually registered cases notified on SIM, with 26.8 sample variation. On Sinan-TB, we saw an E(x) of 8 (95% CI = 5.92-10.08) annually registered cases, with 6.5 of sample variation. The values 21.4 and 8.0 are central measures, closer from truth, but there is no guarantee that this is exactly it. The guarantee is that the relative risk is not above 26.54 and 10.08 and, not under 16.26 and 5.92 for SIM and Sinan-TB, respectively. The narrower the confidence interval, the more precise is the estimate. The precision of these values demonstrates the ability of a result to be repeated in different measures of the same reality.

Regarding the disease incidence coefficient before and after the relationship between databases (Table 1), we saw that that adding deaths not reported on Sinan database would increase the rate of new cases' notification, presenting an increase of incidence until 7.2%.

Table 1: Coefficient of tuberculosis incidence before and after correction from the relationship between Sinan and SIM. João Pessoa, PB, Brazil, 2007 to 2011.

Year	Population	Sinan cases	Incidence coefficient (BC)	Sinan+ SIM	Incidence coefficient (AC)	Incidence increment
2007	683278	396	58.0	412	60.3	3.9
2008	693082	446	64.4	467	67.4	4.6
2009	702234	491	69.9	511	72.8	4.1
2010	725515	416	57.3	446	61.5	7.2
2011	733155	435	59.3	455	62.1	4.6

BC: Before correction; AC: after correction

Underreporting of TB cases from death registries showed a different profile between population groups (Table 2). From total deaths (n=147), 113 were male, and from those, 78 (69.0%) were not previously reported on Sinan. Despite of the occurrence of underreporting being lower among women, we saw that in this group, the proportional percentage of underreporting was superior to men. Women were more likely to not be reported on Sinan in comparison to men (OR = 2.60).

Table 2: Odds ratios of underreported death cases from tuberculosis on Sinan, according to sociodemographic characteristics. João Pessoa, PB, Brazil, 2007 to 2011.

Variables	Total	Not reported - n (%)	Raw Odds	CI 95%	*p*-value
Gender					
Male	113	78 (69.0)	1	-	0.062
Female	34	29 (85.3)	2.60	0.93; 7.29	
Age group					
< 60 years	93	72 (77.4)	1.86	0.89; 3.90	0.098
60 years or more	54	35 (64.8)	1	-	
Education*					
None	19	5 (26.3)	0.40	-	0.196
< 8 years of studies	69	55(79.7)	4.42	1.44; 13.53	0.006
≥8 years of studies	17	8(47.0)	1	0.1; 1.62	
Race/color					
White	32	27(84.4)	2.36	0.84; 6.64	0.096
Non-white	115	80 (69.6)	1	-	

* Cases without education information were excluded.

Regarding age group, people younger than 60 years were 1.86 more likely to not be reported when compared to elderly. To have less than eight years of education presented 4.42 more chances to not be reported in comparison to eight years or more (*p value* <0.05). To not be educated represented a protection factor for reporting (OR = 0.40).

In respect to the race/color, 115 (78.2%) of underreported tuberculosis cases on Sinan were non-white. Although occurrence of deaths were lower among white people, this group presented more likelihood to be not reported (OR = 2.36).

DISCUSSION

The data found in the study showed that within cases reported on SIM, 72.8% did not have access to tuberculosis access in opportune time. The correction of the tuberculosis incidence coefficient during the analyzed period, represented an increase of 4.88% on average; from the inclusion of new disease cases identified through death surveillance

Notification allows to re-run the patient's path, and in different disease situations, it allows to identify possible fragilities of care organization provided to these users and, it allows to track opportunity for transmission[11-12]. Considering death as the most critical outcome for tuberculosis cases, the lack of knowledge about its occurrence of the surveillance sector and, underreporting of cases in the information system, demonstrate fragilities to detect disease cases.

Studies conducted in Brazil[8,10-12] showed underreporting in approximately half of deaths that mentioned TB; a result similar to our study. Such fragility signals deficiencies on the quality and opportunity of access to healthcare for users, which can be associated with factors interdependent of individual, social e programmatic ones. Individual and social perspectives involve risk perception, level of knowledge about health and disease's processes, economic situation, gender and generation relationships, cultural values, access to material resources and ability to receive, metabolize and incorporate information for practical changes in everyday life[13]. In this case, the lack of knowledge about the disease and its severity, difficulty of access (cultural, geographic, and economic) would implicate in late search for health services, in hospital diagnose or, at the death moment.

The institutional or programmatic component connects individual and social components. It consists on local authorities coping with the problem, planning and managing actions, the response ability of involved institutions, adequate and stable financing. It extends to healthcare access, quality of attention, implantation and implementation of care technologies that propitiate the existence of social contexts which favors adoption of prevention measures[13].

Thus, it should be considered that underreporting of TB cases represent an alert state for local managers, because it signals a delay in diagnosis and treatment, causing the lack of expression from promotion and prevention actions in the community. The problem also enunciates deficiency of activities to find respiratory symptoms, identification of suspect cases and, investigation of contacts.

Consensually, tuberculosis is more frequent among men than women, as well as the occurrence of disease underreporting[14-15]. In this study, women had 2.60 more chance to not be reported with the disease on Sinan in comparison to males. A high sensitivity exists to detect Koch bacillus in sputum samples from males, on the other hand, it could constitute an alert signal to underestimate disease cases in females once this diagnostic resource is less sensitive[16].

Regarding age group, people younger than 60 years have more likelihood of tuberculosis underreporting compared to elderly. This finding contradicts studies from the southeast region of Brazil and central region of Italy[14-15,17], where the proportion of not reported individuals was higher among older people. Such divergence can be associated to the organization model of this health attention. Regions valuing the Family Health Strategy (HFS) as open doors to the health system, associate higher proportion of elderly users to their user's profile in comparison to areas not covered by this strategy[18].This can be a differential factor in results found in our study, where the HFS is predominant as health attention model.

The chance of not notifying was significantly higher (4.42 times) when the individual had less than eight years of education those who had more than eight years. Less education reaffirms the strict relationship between the risk of becoming sick in less educated social classes. As a result, it interferes in the process of disease suspicion and identification[19-21]. A study conducted in Rio de Janeiro showed that 58.4% of the sample had less than eight years of education, signaling that insufficient education could have contributed to the lower perception of the disease[8].

The higher percentage of underreporting TB occurrence being more expressive for less educated people can relate with the difference in offer of access to health services and obtainment of early diagnosis. Still, even at an advanced disease stage, individuals of better social conditions have more access to diagnosis, the opposite situation for those found in lower social classes, who maybe, not even at death their diagnosis is confirmed[8,14].

About race, underreporting likelihood was 2.36 times higher among white people. It is estimated that white people have a 3% increased likelihood to consume health services in Brazil[21], and their social benefits lead them to have better resources for health. In this case, underreporting could be associated with higher search for private services, and those services are unaware of the control policy for tuberculosis or, they do not recognize the possibility economically favored clients getting tuberculosis.

It is important to consider the lack of answer from primary care services resulting in searches for emergency and specialized units. Although the studied city had 84% coverage from the Family Health Strategy, this service presents limitations to act as entrance doors in respect to suspicion and confirmation of tuberculosis diagnosis. General/private hospitals, policlinics, private medical clinics and, specialized reference to attend TB cases remain the main service for diagnosis[21-23]. Circumstantially, underreporting would relate to those cases where although the criteria for case definition was met and the disease was identified by the health professional, it was not reported to the public health service or it was not reported in opportune time[8].

Implementation of centers for hospital surveillance, assessment and monitoring of reporting routines by private services would be possible alternatives to induce surveillance actions, especially to recover cases not reported to the sanitary authority. Tuberculosis surveillance can be useful to increase completeness of information systems, to recover and investigate situations of closed cases, to decrease underreporting, to increase the sensitivity of Sinan and SIM, to assess the quality of death registries, to supervise epidemiological surveillance in health establishments, to recover exams of still non-assessed contacts [11-12].

CONCLUSION

The results found signal fragilities in the coordination of care for tuberculosis cases in the municipal health attention network. It denounces low capture of respiratory symptoms, mistakes in clinical conduction, late diagnosis, and flaws when completing the registries. On the other hand, higher expressiveness of underreporting cases in less educated females suggests barriers to search and to obtain basic health services.

Another point that deserves attention is about the quality of the process of producing information. Deficiencies when completing the notification form, lack of observation of the dispatch deadlines and, fragilities in the information flux between notifying units and the epidemiological surveillance can compromise a safe monitoring of the presented reality.

Investments in the surveillance field are needed, to strengthen activities from this service. Linkage is an accessible, low cost technique that can enhance performance of systems through additional and more

reliable information and, it can assist decision-making. Training of technicians to use the database and, training of professionals regarding quality of registry completion for tuberculosis cases are some expressive actions that can minimize or correct existing flaws.

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