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Proposal for tuberculosis death surveillance in information systems

ABSTRACT

OBJECTIVE: To propose a tuberculosis-related death surveillance strategy based on the Brazilian Mortality Information System.

METHODS: Data on 55 tuberculosis-related deaths, which occurred in two large hospitals in Rio de Janeiro, Southeastern Brazil, between September 2005 and August 2006, were obtained from the SIM. These cases were searched and compared with cases in the National Notification System (Sinan). The increment in the number of notifications and completeness of data were evaluated, as well as entry type and outcome in Sinan.

RESULTS: Of the 55 deaths, 28 were registered in Sinan. Comparison between systems allowed for the following corrections: 27 new cases were notified, 14 new notifications performed by the hospitals where death occurred and ten outcomes corrected. This represented an increment of 41/144 (28%) notifications by these two hospitals in 2006. Nine cases, previously classified as unconfirmed tuberculosis were reclassified as bacteriologically confirmed, and another five cases were reclassified from tuberculosis to AIDS as the primary cause of death.

CONCLUSIONS: The proposed surveillance system for tuberculosis-related death was useful to increase data completeness, decrease under-notification and cases with unknown outcome, to evaluate epidemiological surveillance and death certificate quality and to trace previously unidentified contacts.

DESCRIPTORS: Tuberculosis, mortality. Disease Notification. Hospital Mortality. Mortality Registries. Information Systems. Epidemiologic Surveillance.

INTRODUCTION

Epidemiological surveillance, as defined by the Ministry of Health, is a combination of actions that increase knowledge about individual and collective health in order to inform the adoption of prevention and control measures for diseases or illnesses. Mortality data is included among the important data for developing "information for action". Since death from tuberculosis (TB) is avoidable, it is considered a sentinel event, indicating failings of the social network and health system and providing an opportunity to discover other problems in families or the community. Despite its importance, deaths from TB have not been the object of surveillance in Brazil.[1,4,16]

Information systems are fundamental for control and evaluation actions and are important tools in planning and programming. TB cases are registered in the National Notification System (Sinan) from the investigation and follow-up card of a TB case. Under-notification and the detection rate are evaluated by

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comparing national incidence with the estimated new cases from the World Health Organization (WHO). In Brazil, in 2007, 72,000 cases were reported out of an estimated 92,000, which corresponds to a detection rate of 78%.[a] The difference can be explained by the non-detection of cases or by under-registration in Sinan.

Recently, Selig et al[17] described the results of TB-related death surveillance actions, based on the registries of two large hospitals in the municipality of Rio de Janeiro, Southeastern Brazil, in 2005/2006. In considering TB as the primary or associated cause of death, the research identified problems, such as: disease transmission opportunities, errors in clinical performance, high work loads of professionals doing epidemiological surveillance at hospitals, inadequate physical infrastructure and incomplete or inadequate records.

Therefore, due to the lack of human resources to perform death surveillance from records, this study utilized an alternative strategy based on the identification of death through the Mortality Information System (SIM) and previous case detection in Sinan.

The present study aimed to propose a surveillance strategy for TB-related deaths based on the SIM.

METHODS

This descriptive study was based on deaths between September of 2005 and August of 2006, in two large hospitals. The two hospitals, located in the municipality of Rio de Janeiro, were selected for convenience and attend up to 800 patients per day, with open emergency rooms. Death surveillance was performed by the identification of death reports in the SIM of Rio de Janeiro state and subsequent search of the case notification in the state Sinan.

The selected deaths were registered in the SIM and had TB as the primary or associated cause of death.

Death certificates (DCs) that listed TB on a line in field 49 were printed, and the respective cases were sought in Sinan. The notifications were printed to compare information on DCs to data on the identification and confirmation of pulmonary TB, AIDS and other comorbidities. Variable that could be completed of modified were identified. Notifications were considered as related to death, if they occurred within one year or less before death.

Characteristics of the notifications for patients that died were evaluated and described: notifying unit, type of entry and outcomes.

After the comparison of databases, the deaths were eventually reclassified based on the International Classification of Diseases[b] (ICD-10). The DCs identifying unconfirmed pulmonary TB as a primary cause (A16.2) were reclassified as confirmed TB diagnosis (A15.0) based on notification of bacteriologic positive TB. Information contained on positive serology or AIDS permitted the reclassification of deaths that had TB as a primary cause (A15-A19), to death from AIDS (B20-B24).

The study was approved by the Ethics Committee of the Health Department of Rio de Janeiro Municipality, process 11A/05, on March 14, 2005. The directorate of the involved hospitals authorized the study implementation.

RESULTS

There were 55 TB-related deaths identified in the two hospitals through SIM. Of these, the 28 cases were found in Sinan, and 22 had a period between notification and death of less than or equal to one year (Figure 1), with a median of 41 days (1-308). These 28 cases generated 43 non-duplicative notifications, because notifications were done by different units or during the distinct treatments. Although these cases were duly notified, failings in the filling of notifications negatively impacted their analysis.

The comparison of SIM with Sinan permitted the following corrections: 27 (49%) new cases notified, 14 new notifications performed by the unit where death occurred (notifications previously done only by primary health units where patients began treatment) and outcome for ten notifications. In regards to notifications by the two hospitals in 2006, there was an increase of 41/144 (28%).

In Sinan, it was also observed that 25 of the 43 notifications (58%) were performed by hospitals. Among the new notifications identified, the type of entry was readmission after abandonment in three cases and relapse in two cases, which totals 5/28 (18%) inconsistencies for entry type. The identification of TB-related deaths in SIM allowed completion of fields with common variables in the two information systems. The completeness and resulting changes from the strategy are described in Table 2.

In nine cases, the review of pulmonary TB confirmation allowed reclassification of the primary cause of death, from pulmonary TB without mention of bacteriological confirmation or histology (A16.2) to pulmonary TB

[a] Ministério da Saúde. Secretaria da Vigilância em Saúde. Programa Nacional de Controle da Tuberculose. Situação da Tuberculose no Brasil e no mundo. [s.d.] [cited 2009 Oct 22]. Available from: http://portal.saude.gov.br/portal/arquivos/pdf/apresentacao_tb_2009.pdf
[b] World Health Organization. International Statistical Classification of Diseases and Related Health Problems. 10.ed. 2007 [cited 2009 Oct 23]. Available from: http://www.who.int/classifications/apps/icd/icd10online/

Table 1. Notifications of deaths in hospitals. Rio de Janeiro municipality, Southeastern Brazil, 2005-2006.

Notification	n/N (%)
Death	28/55 (51)
Notifications by hospitals (more than one notification per patient)	25/43 (58)
New cases	19/28 (68)
Type of entry – relapse or abandonment, 1st notification in Sinan	5/28 (18)
Type of entry – not known	4/28 (14)
Notification related to death (< one year before death)	22/28 (79)
Notification by the unit where death occurred	14/28 (50)
Cases with death as final outcome	4/28 (14)
Previous notifications with outcome as abandoned	2/43 (5)
Notifications with unknown outcome	29/43 (67)
Prior notifications with outcome as cure[a]	7/43 (16)

Source: National Notification System (Sinan)
[a] One case with two TB epidsodes with the outcome as cure.
n = number verified
N = total number considered

Table 2. Proportion of notifications with fields filled in the information systems and resulting increase from linkage. Rio de Janeiro municipality, Southeastern Brazil, 2005-2006.

Variable	SIM n (%)	Increase in SIM n (%)	Sinan n (%)	Increase in Sinan n (%)
Race / Color	53/55 (96)	-	21/28 (75)	6/28 (21)
Education	49/55 (89)	3/55 (5)	23/28 (82)	4/28 (14)
Occupation	30/55 (55)	3/55 (5)	17/28 (61)	4/28 (14)
Confirmed pulmonary TB	6/49 (12)	9/49 (18)	9/22 (32)[a]	-
HIV antibody test	15/55 (27)	5/55 (9)	11/28 (39)	9/28 (32)

SIM: Mortality Information System; Sinan: National Notification System
[a] Excluded the six cases in which death occurred in a period longer than one year from notification.

confirmed by sputum microscopy (A15.0). Additionally, the information on AIDS in Sinan allowed reclassification of the primary cause of death from TB to AIDS in five cases. In seven cases, the patients presented chronic comorbidities reported in Sinan and not mentioned in the DC. There was concordance in only one case, with the mention of diabetes mellitus in Sinan and SIM.

The systemization of procedures allowed for developing a proposal for TB-related death surveillance based on the SIM (Figure 2). According to this proposal, every TB case with an outcome of death should be notified by the unit in which death occurred, independent of prior notification. If the case was previously reported, the notifications should be linked. The notification referring to the preceding event (cure, abandonment, transfer, death or multidrug-resistant TB) should be adequately closed after investigation and analysis.

DISCUSSION

Death surveillance using the SIM produced a substantial increase in notifications performed by hospitals and modest increase in data completeness for both information systems, as well as the reclassification of SIM registrations. With the procedures utilized, we formulated a proposed algorithm for surveillance of TB-related deaths. The efficacy obtained for data retrieval was inferior to the surveillance of TB deaths from hospital death records,[17] which we perceived empirically as impractical for the majority of hospitals due to the high work load of professionals and the time necessary for case investigations.

In 2003, the WHO classified the Brazilian SIM as medium quality,[12,c] with sensitivity between 70% and 90%. An evaluation of the SIM by indirect demographic methods suggests that the coverage is satisfactory, principally in the South and Southeast regions, where it is 90% for men and 87.4% for women.[6] According to the Ministry of Health, SIM has greater coverage than Sinan.[c] This indicates that the death of a patient with TB may not be reported.[d] Therefore, we decided to recommend death surveillance through the SIM.

The under-notification of TB-cases with the outcome of death is not a new finding. In a recent publication, the WHO recommends the creation of strategies based on a mortality information system that allows the recovery of unreported cases.[d] In the state of Rio de Janeiro, an under-notification of 58% in 1998 was reported.[16] In other Brazilian states, the same phenomenon was reported: in the municipality of São Paulo, Southeastern Brazil, under-notification was 50% in the East Zone in 2001,[13] 49% in 2002[10] and 44% during the period of 2002–2004;[e] in Fortaleza, Northeastern, it was 67% during the period 1999–2003.[5] In 2008, the completeness of essential fields in the municipality of Rio de Janeiro was 91% for race/color, 100% for education and 77% for occupation, which was not observed in the sample of deaths studied here.[f] It is possible that the low completeness in studied cases is related to an

[c] World Health Organization. Global Tuberculosis Control Surveillance, Planning, Financing. Geneva; 2009 [cited 2009 Oct 20]. Available from: http://www.who.int/tb/publications/global_report/en/

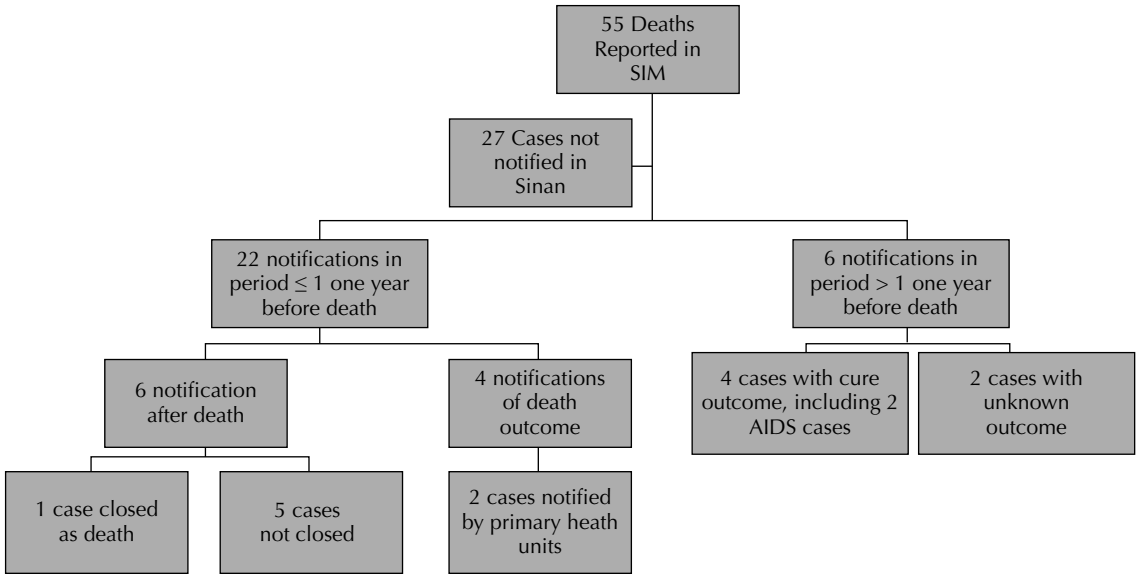

Figure 1. Temporal relationship among notifications in the information systems of deaths associated with tuberculosis that occurred in hospitals. Rio de Janeiro municipality, Southeasten Brazil, 2005-2006.

increased frequency of individuals living in a homeless situation among those that die from TB.[17]

The proposal for death surveillance based on the SIM involves cooperation between epidemiological surveillance and the vital statistics sector on TB control programs, which has already been routinely occurring in the Woman, Child and Adolescent Health Program.[g] A similar strategy to link information systems was proposed by Maia-Elkhoury et al,[11] in 2007, with the goal of decreasing under-notification of visceral leishmaniasis.

Besides data quality improvement, the proposed death surveillance allowed epidemiologic and operational reflection. The high number of notifications performed by hospitals indicates the importance of hospital care for a disease that should be mostly managed in primary care, which also occurs in the municipality of São Paulo.[7] The amount of new cases followed by death indicates their gravity and highlights the delay in diagnosis as previously described[7] and the potential difficulty in access to the health system. It is expected that when TB control improves, the number of notifications by hospitals and the number of new cases with the outcome of death will decrease.

Evaluation of the identified mistakes, such as "relapse" as a type of entry in a first notification in Sinan, should be a warning of database quality and the collection of information in hospital units. In the majority of deaths notified by hospitals, the case outcome was not reported, which is an indicator of operational failings in the hospital epidemiological surveillance.[2] The number of cases with unknown outcome complicates the evaluation of disease control actions.[8] The decentralization of the Sinan to hospitals could contribute to improve the utilization of data about patients registered in the system, avoiding under-notifications and improving connections between patients and the team of health professionals in the notifying units of the information system. The number of individuals that died from TB after a cure event generates questions about the criteria for cure and the importance of a post-treatment surveillance system.[14]

In addition, database linkage allows for the reclassification of some cases. Deaths attributed to TB and notified in Sinan, with serology confirmed human immunodeficiency virus (HIV) could be correctly classified as a death from AIDS (primary cause), with TB as an associated cause. Another shortcoming to potentially correct through linkage is the number of TB deaths without bacteriological or histological confirmation (ICD A16.2). According to Laurenti (2006), death investigations can change the analysis of mortality profile.[d] Santos (2006) highlights the lower average number of causes mentioned in Rio de Janeiro state in comparison to São Paulo, in the DCs with TB as a primary cause,[15] which weakens the evaluation of TB-related comorbidities in Rio de Janeiro.

For our algorithm, we began from the Ministry of Health's premise notification of case death should be performed by the unit where the death occurred, through a notification even if a prior notification had been

[d] Laurenti R, Jorge MHPM. O Sistema de Informações sobre Mortalidade: passado, presente e futuro. São Paulo: Centro Colaborador da OMS para a Família de Classificações em Português; 2006. (Série divulgação, 11).

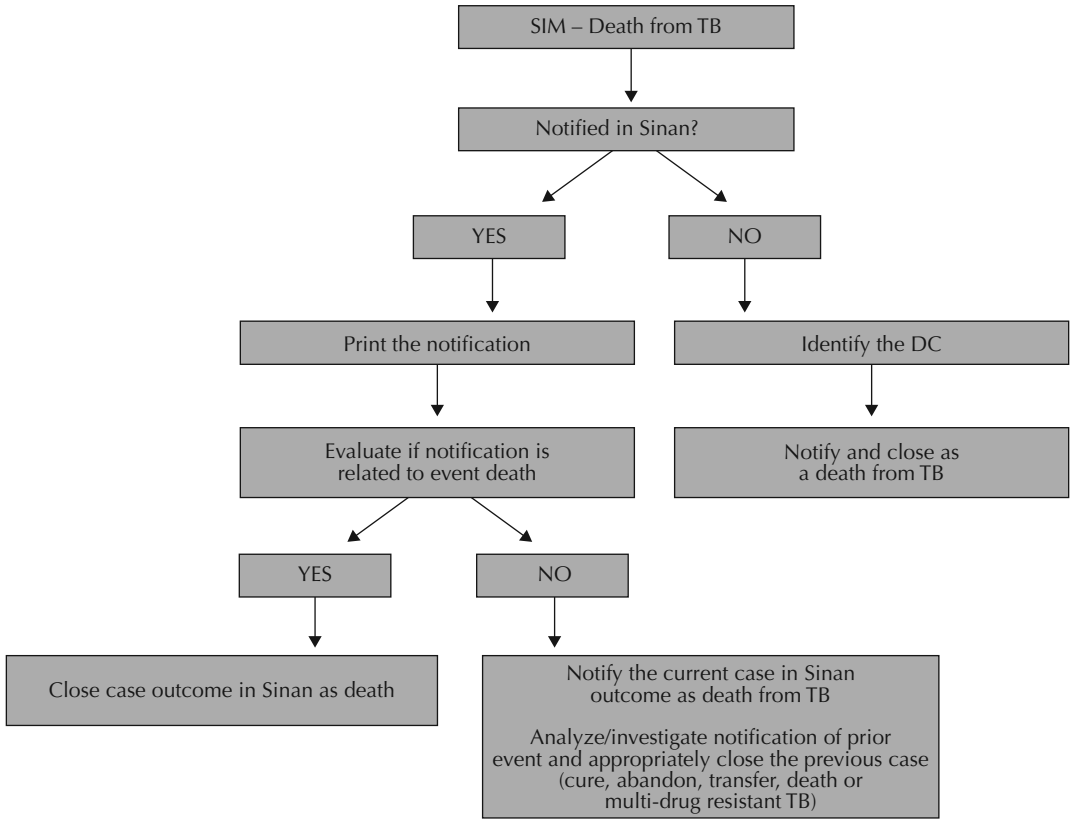

Figure 2. Proposal for epidemiological surveillance strategy of deaths from tuberculosis. Rio de Janeiro municipality, Southeasten Brazil, 2005-2006.

performed in another health unit. In the present study, of the notifications closed by death, two cases were closed by prior notification by a primary health unit, more than 30 days before death. It is possible, for example, that the case had been reported, initiated and later abandoned treatment, and, some time later, the death was reported to the primary health unit. In such cases, we recommend that the TB control program contact the health unit to understand the outcome in the notification, which was incorrectly reported as death. The described hypothesis could generate a false reduction in the rate of abandonment, in addition to the non-reporting of the case by the unit where death occurred. This is an example of procedures that, besides correcting the database and improving analysis, facilitate the supervision of the work process in the epidemiological surveillance of the health unit and hospital. In our study, where case investigation at the health unit was not a possibility, the cut-off point for the linkage of notifications was a period of one year. This point was arbitrary, based on the maximum treatment time for a TB case susceptible to first line drugs, and deserves further consideration and validation.

One of the main goals of epidemiological surveillance in cases of direct disease transmission is the interruption of transmission. The notifications register the path traveled by the patient, which can allow for the discovery of opportunities to interrupt transmission. A patient that progressed to death without prior notification was undetected by the TB control program, and therefore, we assume that their contacts have not been evaluated.[9] In this situation, the health units should be actuated for a domestic visit, considering the risk of illness among contacts is at least 15 times greater than among the general population.[3,i] A function of epidemiological surveillance is to provide feedback with data to the health units and their professionals, which can encourage the professionals to perform notifications.

The current study has limitations, since it evaluated a small sample of cases from only two hospitals. It is necessary to validate this algorithm in the municipality of Rio de Janeiro and others. Nonetheless, we conclude that death surveillance of TB can be useful to increase the completeness of information systems, increase the proportion of cases with known outcome, correct the Sinan and SIM, decrease under-notification, evaluate the quality of DCs, supervise epidemiological surveillance by hospitals and health units and search for contacts unevaluated by health teams.

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