



Estimated underreporting of congenital syphilis deaths in Recife, Pernambuco, Brazil, 2010-2016: linkage between the mortality information system and the notifiable health conditions information system*

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Martha Maria de Albuquerque Belo¹ –  orcid.org/0000-0002-1908-7690

Conceição Maria de Oliveira² –  orcid.org/0000-0002-2220-5782

Sheyla Carvalho de Barros³ –  orcid.org/0000-0001-5399-0296

Lívia Teixeira de Souza Maia⁴ –  orcid.org/0000-0002-0161-7729

Cristine Vieira do Bonfim⁵ –  orcid.org/0000-0002-4495-9673

¹Secretaria de Saúde do Recife, Programa de Residência Multiprofissional em Saúde Coletiva, Recife, PE, Brazil

²Secretaria de Saúde do Recife, Diretoria Executiva de Vigilância à Saúde, Recife, PE, Brazil

³Universidade Federal de Pernambuco, Programa de Pós-Graduação em Saúde Coletiva, Recife, PE, Brazil

⁴Fundação Oswaldo Cruz, Instituto Aggeu Magalhães, Recife, PE, Brazil

⁵Fundação Joaquim Nabuco, Diretoria de Pesquisas Sociais, Recife, PE, Brazil

Abstract

Objective: To estimate underreporting of fetus and infant deaths having congenital syphilis as their underlying or associated cause in Recife, Pernambuco, Brazil, between 2010-2016. **Methods:** Probabilistic database linkage was carried out between congenital syphilis cases recorded on the Notifiable Health Conditions Information System and fetus and infant deaths due to congenital syphilis recorded on the Mortality Information System. **Results:** 170 fetus and infant congenital syphilis deaths were matched. Fetus and infant deaths due to congenital syphilis were underreported by 80.9% on the Notifiable Health Conditions Information System and by 7.0% on the Mortality Information System, accounting for an increase of 2.3% and 7.0% in the final databases, respectively. **Conclusion:** The underreporting identified compromises knowledge of the true magnitude of deaths caused by this disease.

Keywords: Syphilis, Congenital; Fetal Death; Epidemiological Monitoring; Information Systems; Vital Statistics; Cross-Sectional Studies.

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Correspondence:

Martha Maria de Albuquerque Belo – Rua dos Navegantes, No. 2862, Ed. Santa Angélica, Boa Viagem, Recife, PE, Brazil.

CEP: 51111-080

E-mail: marthaabelo@gmail.com

Introduction

Congenital syphilis is a global public health problem, responsible for serious sequelae in live births, as well as fetal and infant deaths.^{1,2} Its occurrence reflects failures in maternal and child health care, even though the disease can be prevented, diagnosed, and treated during prenatal care.³

In Recife, the congenital syphilis incidence rate was 29.1 cases per 1000 live births, in 2016.

In 2016, there were estimated to be approximately half a million fetal and infant deaths due congenital syphilis per year globally.⁴ With the aim of reducing infant mortality, one of the targets set by the Sustainable Development Goals defined at the United Nations General Assembly, is to have eliminated congenital syphilis by 2030, reducing its incidence to the acceptable level of 0.5 cases per 1000 live births.⁵

In Brazil, congenital syphilis incidence increased continuously in the country's five macro-regions between 2010 and 2015. The Northeast and Southeast regions had the highest incidence rates, reporting 2.7 and 6.9 cases per 1000 live births, respectively. During the same period there was also an increase in the average rates of infant deaths, miscarriages and stillbirths per year. In 2016, the highest average rates of infant mortality due to congenital syphilis were found in the North (6.27 cases per 100,000 live births), Southeast (5.50 cases per 100,000 live births), and Northeast (5.28 cases per 100,000 live births) of Brazil.⁶

In 2016, the state of Pernambuco recorded a congenital syphilis incidence rate of 11.8 cases per 1000 live births, exceeding the national average of 6.5 cases per 1000 live births. In Recife, the congenital syphilis incidence rate was 29.1 cases per 1000 live births, the highest in the state that year.⁷

Notification of congenital syphilis is compulsory for all World Health Organization (WHO) member countries, and it is mandatory to communicate all cases to health authorities and to investigate them. In Brazil, congenital syphilis cases and deaths are monitored via the Notifiable Health Conditions

Information System (SINAN) and the Mortality Information System (SIM).⁸

These systems provide information on the characteristics of reported cases, care provided to patients and underlying cause of death, allowing important indicators to be built in order to outline the health-disease profile of a region.⁹ However, lack of data quality and underreporting on health information systems cause the true magnitude of diseases to be underestimated.^{10,11}

Underreporting of congenital syphilis deaths refers to a suspected or confirmed case which, once recognized by the health professional, was not notified to the competent authority;⁷ or that there was failure to fill in the required fields on the notification and investigation forms; or that there were problems in identifying the underlying causes or causes associated with death on Death Certificates.¹²

The objective of this study was to estimate underreporting of fetal and infant deaths having congenital syphilis as their underlying or associated cause, occurring in the capital city of Recife, state of Pernambuco, Brazil, between 2010 and 2016.

Methods

This was a cross-sectional study, conducted in Recife, using secondary data for the period 2010-2016.

The city of Recife occupies an area of 218,435 km², divided into 94 neighborhoods which are distributed between eight health districts, all of which were included in this study. In 2016, Recife had an estimated population of 1,625,583 inhabitants, 19,142 (1.2%) of whom were under 1 year of age.¹³ The local municipal health network for maternal and child care is comprised of 122 Family Health Strategy centers, 268 Family Health Strategy teams, four maternity hospitals and a pediatric hospital.¹⁴

The study data sources were the SINAN and SIM information systems. SINAN is the main instrument for collecting compulsory notification data. Notifications of congenital syphilis are entered on SINAN along with all corresponding information about occurrence of miscarriages, stillbirths, and live births, thus allowing monitoring of the progression of each congenital syphilis case. The data recorded for each notification provides the basis for epidemiological and

operational calculations for the whole of Brazil.⁷ The main document used by the SIM system is the Death Certificate. SIM is a valuable resource for the National Epidemiological Surveillance System, especially when there are flaws in case recording on SINAN.¹⁵

We analyzed all congenital syphilis notifications on SINAN and records of fetal and infant deaths held on SIM. Initially, we applied probabilistic linkage¹⁶ between the two databases using ReLink III version 3.1.6.3160. Notified cases of congenital syphilis recorded on SINAN were linked to fetal and infant deaths recorded on SIM which had congenital syphilis as their underlying or associated cause (codes A50 to A50.9 of the 10th Revision of the International Statistical Classification of Diseases and Related Health Problems, ICD-10).

The variables used in the probabilistic linkage were: patient name; sex; date of birth; mother's name; and neighborhood of residence. Records without names were excluded.

A set of steps was following when performing the probabilistic linkage, as follows:

- 1) standardization of the variables held on the database (accents, graphic elements, cedillas, spaces, and special characters were removed; and identical field formats were kept in different files);

- 2) creation of logical record blocks (blocking), i.e. creating common sets of records based on identification codes;

- 3) approximate comparisons of character strings, with the aim of controlling phonetic and spelling errors, by applying algorithms;

- 4) calculation of scores that indicate the degree of agreement between pairs of records formed;

- 5) determining thresholds for linking pairs of records, which were classified as exact matches, uncertain matches, and non-matches; and

- 6) reviewing uncertain matches and reclassifying them as exact matches or non-matches.

The scores were calculated by ReLink III. Scores higher than 21.7 were considered exact matches, those lower than -6.9 were non-matches, while intermediate scores were considered to be uncertain matches. Two researchers reviewed the uncertain matches, and in case of disagreement, a third researcher was consulted, according to the following tie-breaking criteria: patient's name, mother's name, and date of birth. After having been reviewed, uncertain matches were reclassified as exact matches or non-matches.

The thresholds established for the patient's name were 92% (probability of accuracy), 1% (probability of error) and 85% (agreement between both records); and for date of birth, 90%, 5% and 65%, respectively. The phonetic keys of first and last names (patient and mother), sex and year of birth were used to identify duplicates on the SINAN and SIM databases. During the application of the linkage method, some death records became linked to more than one notification of the same individual on the SINAN database. In order to eliminate these repetitions, notifications with the most recent diagnosis date were excluded.

After performing probabilistic linkage, a manual search was performed between cases of congenital syphilis reported on SINAN, with progression to death from this cause, as well as a manual search of all records of fetal and infant deaths held on SIM and which occurred during the study period. The purpose of this step was to identify notifications that progressed to death from congenital syphilis held on SINAN but recorded on SIM as death from another cause. The data were analyzed and tabulated using Epi Info version 7.2.2.6.

The research project was approved by the *Instituto de Medicina Integral Prof. Fernando Figueira* Human Research Ethics Committee, as per Opinion No. 2.543.590, issued on March 14, 2018, and the Recife Health Department gave consent for accessing the databases.

Results

Between 2010 and 2016, 2,983 cases of congenital syphilis were notified on SINAN. Of these notifications, 63 (2.2%) progressed to death. In the same period, we identified 3,258 records of fetal and infant deaths on SIM, of which 241 (7.4%) were due to congenital syphilis.

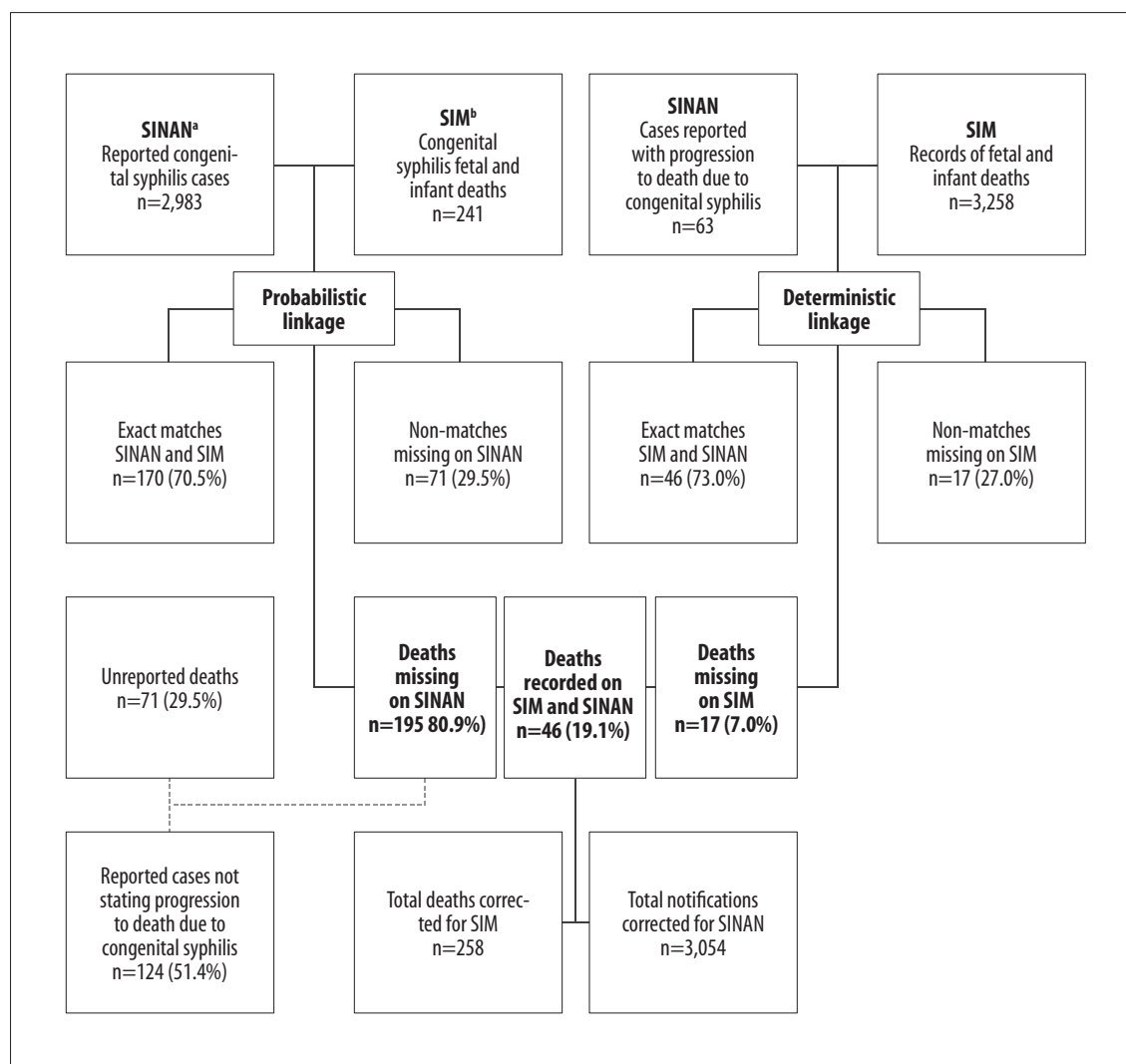
Once matching between 170 (70.5%) notifications and records of fetal and infant deaths from congenital syphilis had been performed, out of the 241 fetal and infant deaths with congenital syphilis as the underlying or associated cause held on SIM, 71 (29.5%) were not reported as progressing to death from congenital syphilis on SINAN (Figure 1).

The manual search performed on the 63 SINAN notifications having death from congenital syphilis as their outcome and on all fetal and infant deaths held on SIM, identified 46 exact matches. However, 17 notifications with this outcome on SINAN, were not found on SIM. This result allowed us to observe that of the 241 deaths from congenital syphilis recorded on

Table 1 – Congenital syphilis death underreporting on the Notifiable Health Conditions Information System and on the Mortality Information System, Recife, Pernambuco, Brazil, 2010-2016

Underreporting	SINAN ^a N (%)	SIM ^b N (%)
Unreported deaths	71 (29.5%)	17 (7.0%)
Cases reported without stating progression to death due to congenital syphilis	124 (51.4%)	–
Total unreported deaths	195 (0.9%)	17 (7.0%)
Total deaths identified on SIM^b used for proportional calculation of underreporting^c		241

a) SINAN: Notifiable Health Conditions Information System; b) SIM: Mortality Information System; c) Total deaths mentioning congenital syphilis as the underlying or associated cause of death on SIM (N=241) were used to calculate congenital syphilis death underreporting on SINAN and on SIM.



a) SINAN: Notifiable Health Conditions Information System; b) SIM: Mortality Information System.

Figure 1 – Linkage between reported congenital syphilis case database and congenital syphilis fetal and infant deaths database, Recife, Pernambuco, Brazil, 2010-2016

SIM, 46 (19.1%) had notification of congenital syphilis on SINAN which included information on case outcome as death from congenital syphilis.

The results showed underreporting on both systems (Table 1).

On SINAN, 71 (29.5%) death records were not found and 124 (51.4%) notifications of congenital syphilis were not classified as having progressed to death from the disease. Summing non-notified deaths and notifications that did not record progression to death from congenital syphilis, a total of 195 (80.9%) underreported cases of fetal and infant deaths from congenital syphilis were found on SINAN. Moreover, we found that 17 (7.0%) notifications held on SINAN, with progression to fetal or infant death from congenital syphilis, were not found on the SIM, within the study period.

There was an increase of 2.3% in the final SINAN database, from 2,983 to 3,054 notifications of congenital syphilis. In the case of the SIM database, the total increase was 7.0%, from 241 to 258 records of fetal and infant deaths from/with congenital syphilis. Statistical testing was not carried out to verify the significance of this increase.

Discussion

Considering the deaths from congenital syphilis that occurred in Recife between 2010 and 2016, when linking the SINAN and SIM databases we identified 71 cases recorded on SIM that were not recorded on SINAN; and 17 cases reported on SINAN, but with no record on SIM. These findings point to underreporting of deaths from congenital syphilis on both systems. Proportionally, the increase of cases on SINAN (2.3%) was lower than on SIM (7.0%).

Despite the low number of cases added to the databases, it is important to highlight (i) the preventable nature of congenital syphilis during pregnancy and (ii) the fact that it is a disease the notification of which is compulsory. The underreporting found in the study reflects the fragility between maternal and child health care and epidemiological surveillance¹² in the municipality.

A first limitation of the research was the use of secondary data with flaws in the process of entering variables on the information systems, leading to possible errors, when greater data accuracy, completeness and reliability is expected. This limitation

can not only compromise the quality of the records, but also cause biases in the results obtained. Despite this, the database linkage methodology, widely used to identify underreporting on information systems,^{8,13} does not require accuracy as to the values of the variables between matched records, minimizing the problem of not finding all data for the same patient on the two different databases. However, the incompleteness of the variables chosen for linkage, as well as the presence of homonyms, may have reduced the number of matches. Application of the linkage technique aims to reduce these inconsistencies in information systems.

Another limiting factor of the study was that cases of syphilis in pregnant women reported on SINAN were not included, which may have underestimated fetal and infant deaths from congenital syphilis. However, the data contained in the notifications of syphilis in pregnant women are limited when compared to those contained in congenital syphilis notifications.

Death from congenital syphilis is considered a sentinel event in prenatal care,¹⁷ this being a concept that demonstrates the possibility of avoiding death, through effective actions in health services, and the importance of its notification/investigation being carried out by the epidemiological surveillance service, in the sense of proposing prevention measures.

Finding underreporting related to case outcomes on SINAN reflects the low quality of the data entered,^{18,19} hindering reliable analysis of congenital syphilis morbidity and mortality in the municipality. The main function of data on diseases is to provide a framework for the implementation of policies to promote and protect the health of the population, in addition to providing information for surveillance and epidemiological analysis.²⁰

It is important to emphasize that investigation of reported cases of congenital syphilis is carried out by the epidemiological surveillance service, and that the 'case progression' variable field on the congenital syphilis notification/investigation form is mandatory. The existence of underreporting related to case outcomes reinforces the importance of careful and accurate transfer of data to the notification/investigation forms and its input on SINAN.²¹ Above all, this finding points to the need to strengthen municipal epidemiological surveillance services throughout the country with regard to permanent monitoring of reported cases of congenital syphilis, and this joint

action is essential for Brazil to find the way to meet the goals for congenital syphilis elimination.^{21,22}

Similar results have been identified in other Brazilian cities, where underreporting of fetal and infant deaths from congenital syphilis ranged from 67% to 90%.^{8,13,23} This variation in the proportions of underreporting of deaths on SINAN hinders analysis of mortality indicators for congenital syphilis, preventing true knowledge of this outcome.²⁴ On SINAN, both non-notification and failure to enter data on the progression of cases to death from congenital syphilis, as identified in this study, imply consequences for the effectiveness of control actions, especially because SINAN is the main data collection instrument used by the epidemiological surveillance services.

Underreporting of fetal and infant deaths due to congenital syphilis on SIM was also found by another study that used linkage between SINAN and SIM records.²⁵ Studies indicate that one of the causes associated with the underreporting found on SIM is the quality of Death Certificate information. Provision of this information is entrusted to medical professionals, and it has been found to be unsatisfactory, whether with regard to the recording of variables or the definition of the underlying cause or cause associated with death.^{26,27}

Underreporting of fetal and infant deaths on SIM can be minimized through data analysis by the Infant and Fetal Death Prevention Committees. These committees should include congenital syphilis as one of the causes of death if the mother or child has been diagnosed with the disease, and notify the case on SINAN.²³ One of the attributes of the Infant and Fetal Death Surveillance strategy implemented in Brazil with effect from 2010, is to improve the quality of records of fetal and infant deaths by investigating these deaths.⁸ When done jointly with health care services, surveillance covers the processes of notification, investigation, discussion and classification of the avoidability of these deaths, contributing to the veracity of the information included on information systems.¹⁷

Certain gaps may explain notifications with progression to death held on SINAN not being identified on SIM: failures in the linkage process, 'case closure' variable typing errors and the probability of death having occurred in another municipality. The possibility therefore exists that these cases of congenital syphilis did not have death as their outcome. The existence of underreporting on SIM contributes not only to lack of knowledge about fatal cases of congenital syphilis, but also contributes to their invisibility, despite the fact that such knowledge could inform municipal health management decision-making.^{23,28}

The database linkage carried out in this study, gave rise to an increase in notifications of deaths from congenital syphilis on both information systems: the increase on the SINAN database was 2.3%, while on SIM it was 7.0%. Variations like these have also been identified in other studies, which used the database linkage technique in order to improve the information contained on these systems.^{23,25}

The results presented indicate underreporting of fetal and infant deaths from congenital syphilis on the SINAN and on the SIM databases in the city of Recife. Probabilistic linkage proved to be an easy to access technique with low operating cost, which can be used in the routine of syphilis surveillance services. Linkage can facilitate monitoring of underreporting and contribute to the quality of information used to support the implementation of public policies and strategies for the prevention of congenital syphilis.

Authors' contributions

Belo MMA, Oliveira CM and Bonfim CV took part in the study concept and design, data analysis and drafting the manuscript. Barros SC and Maia LTS took part in data interpretation and critically reviewing the intellectual contents. All the authors have approved the final version of the manuscript and are responsible for all aspects thereof, including the guarantee of its accuracy and integrity.

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