

Agreement and completeness of data on live births and infant deaths

Concordância e completude dos dados sobre nascidos vivos e óbitos infantis
 Concordancia y completitud de los datos sobre nacidos vivos y defunciones infantiles

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Abstract

Objective: To assess the quality of data (agreement and completeness) on infant deaths in the Mortality Information System (SIM) and in the Information System on Live Births (Sinasc), Recife, Pernambuco, Brazil.

Methods: Cross-sectional study with data on infant deaths captured in Sinasc and SIM. For the deaths, the period 2013-2016 and the live births of 2012-2016 were used. The deterministic linkage was used. The percentage of incompleteness of 10 variables common to both bases pre- and post-linkage was calculated. The agreement was assessed by the Kappa index for qualitative variables and by the intraclass correlation coefficient (ICC) for the quantitative variables.

Results: It was possible to relate 96.64% of the deaths to their respective declaration of live birth. All analyzed variables were classified as excellent (less than 5% incompleteness), pre- and post-linkage. In Sinasc, the greatest incompleteness was in the variable length of pregnancy (1.55%) and in the SIM, the number of stillbirths (2.89%). The agreement was classified as almost perfect for all qualitative variables (Kappa between 0.8 and 1). All quantitative variables were excellent (ICC greater than 0.75).

Conclusion: Despite advances in the quality of SIM and Sinasc, there were still problems of completeness of variables, especially in SIM. The linkage contributed to the improvement of information for the analysis of infant deaths by health services and for research. It is a technique that is easy to access and low operational cost, which can be included in the routine of infant mortality surveillance for the continuous improvement of information.

Resumo

Objetivo: Avaliar a qualidade dos dados (concordância e completude) dos óbitos infantis no Sistema de Informações de Mortalidade (SIM) e no Sistema de Informações sobre Nascidos Vivos (Sinasc), Recife, Pernambuco, Brasil.

Métodos: Estudo transversal com dados de óbitos infantis capturados no Sinasc e no SIM. Para os óbitos, foi utilizado o período 2013-2016 e para os nascidos vivos, o de 2012-2016. Foi utilizado o *linkage* determinístico. Calculou-se a porcentagem de incompletude de 10 variáveis comuns a ambas as bases, antes e após a vinculação das bases de dados. A concordância foi avaliada pelo índice Kappa para variáveis qualitativas, e pelo coeficiente de correlação intraclass (ICC do inglês *intraclass correlation coefficient*) para variáveis quantitativas.

Resultados: Foi possível relacionar 96,64% dos óbitos às respectivas declarações de nascidos vivos. Todas as variáveis analisadas foram classificadas como excelentes (menos de 5% de incompletude), antes e após

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a vinculação das bases de dados. No Sinasc, a maior incompletude ocorreu na variável duração da gestação (1,55%), e no SIM, no número de natimortos (2,89%). A concordância foi classificada como quase perfeita para todas as variáveis qualitativas (Kappa entre 0,8 e 1). Todas as variáveis quantitativas foram classificadas como excelentes (ICC maior que 0,75).

Conclusão: Apesar dos avanços na qualidade do SIM e do Sinasc, ainda houve problemas de completude das variáveis, principalmente no SIM. A vinculação das bases de dados contribuiu para aprimorar as informações para a análise de óbitos infantis pelos serviços de saúde e para pesquisa. O *linkage* uma técnica de fácil acesso e baixo custo operacional, que pode ser incluída na rotina de vigilância da mortalidade infantil para a melhoria contínua das informações.

Resumen

Objetivo: Evaluar la calidad de los datos (concordancia y completitud) de defunciones infantiles en el Sistema de Información de Mortalidad (SIM) y en el Sistema de Información sobre Nacidos Vivos (Sinasc), Recife, estado de Pernambuco, Brasil.

Métodos: Estudio transversal con datos de defunciones infantiles registrados en el Sinasc y en el SIM. Para las defunciones, se utilizó el período 2013-2016 y para los nacidos vivos, 2012-2016. Fue utilizada la vinculación determinística. Se calculó el porcentaje de incompletitud de 10 variables comunes de ambas bases, antes y después de su vinculación. La concordancia fue evaluada por el índice Kappa en las variables cualitativas y por el coeficiente de correlación intraclass (ICC, por sus siglas en inglés *intraclass correlation coefficient*) en las variables cuantitativas.

Resultados: Fue posible relacionar 96,64% de las defunciones con las respectivas declaraciones de nacidos vivos. Todas las variables analizadas fueron clasificadas como excelentes (menos de 5% de incompletitud), antes y después de la vinculación de las bases de datos. En el Sinasc, la mayor incompletitud ocurrió en la variable duración de la gestación (1,55%) y, en el SIM, en el número de mortinatos (2,89%). La concordancia fue clasificada como casi perfecta en todas las variables cualitativas (Kappa entre 0,8 y 1). Todas las variables cuantitativas fueron clasificadas como excelentes (ICC mayor a 0,75).

Conclusión: A pesar de los avances en la calidad del SIM y del Sinasc, aún hay problemas de completitud de las variables, principalmente en el SIM. La vinculación de las bases de datos contribuyó en la mejora de la información para el análisis de defunciones infantiles por parte de los servicios de salud y para estudios. La vinculación es una técnica de fácil acceso y bajo costo operativo, que puede incluirse en la rutina de la vigilancia de la mortalidad infantil para la mejora continua de la información.

Introduction

The infant mortality rate estimates the risk of a child dying during the first year of life and reflects inequalities, being considered one of the most sensitive indicators of a population's life and health condition.^(1,2) Infant mortality rate, defined as the number of deaths per 1,000 live births. Its reduction is on the global agenda of developed and developing countries and constitutes a challenge for health systems. The 4th Millennium Development Goal was to reduce child mortality by 75 per cent over the period 1990 to 2015; Brazil was able to comply in advance by reducing from 29.7 deaths per thousand live births in 2000 to 15.7 deaths per thousand live births in 2011. The overall infant mortality rate declined by 53.1 percent from 64.7 deaths per 1000 live births in 1990 to 30.3 in 2016. In Brazil the infant mortality rate in 1990 was 52.6 deaths per 1000 live births, decreasing to 14.6 in 2016, however the country presents a great variability in infant mortality rates, with the largest being in the North and Northeast regions.⁽³⁾ For the state of Pernambuco in 2016 the infant mortality rate was 13.94 per 1000 live births. For Recife the infant mortality rate 12.09 per 1000 live births.⁽⁴⁾ In order to monitor and evaluate compliance with the targets for reducing child

mortality, it is necessary that the vital statistics information systems have reliable data.^(5,6)

The main information recorded by the health sector on the occurrence and the circumstances of births and deaths should be used by civil registration agencies to increase notification and official registration.⁽⁷⁾ Admittedly to the monitoring of sustainable development goals (ODS), will depend on the availability of continuous, detailed and specific vital statistics. In this sense, two ODS objectives relate to improving the civil registry and vital statistics.⁽⁸⁾

For proper monitoring of progress in reducing infant mortality, it is vital to have reliable and complete vital statistics information.^(5,9) Increasingly, vital statistics systems are being recognized as drivers of human rights, health and development programs, especially for women and children.⁽⁹⁾ In low-income countries, where vital statistics systems are precarious, the burden of maternal and infant deaths is also high.⁽⁵⁾ Therefore, they need updated estimates and quality information to monitor the levels and trends of maternal and infant mortality.⁽⁶⁾ This information is necessary for the development of health indicators and influences policy development, research and program funding, and health care measures.⁽¹⁰⁾

Vital statistics systems that work properly bring benefits not only for the formulation of public poli-

cies but also for the health of the population.⁽¹¹⁾ The maintenance of these systems is necessary to maintain data reliability, since they provide information on births and deaths, and subsidize actions that seek to improve the quality of public health.⁽¹²⁾

In Brazil, the Ministry of Health implemented the Mortality Information System (SIM) in 1975 with the purpose of incorporating into the daily routine of the health secretariats the systematization of data on deaths.⁽¹³⁾ The system is fed by the Death Certificate (DC), which has information essential for epidemiological surveillance.⁽¹⁴⁾ In addition, the SIM facilitates the investigation of facts about deaths, thus offering subsidies for the investigation of infant deaths through data as the basic cause of death.⁽¹⁵⁾

Another important source of information for the monitoring of infant mortality is the Live Birth Information System (Sinasc), which is fed by the Certificate of Live Birth (CLB) and has data on the mother and newborn from pre-natal until birth.⁽¹⁶⁾ Implemented in 1990 by the Ministry of Health, Sinasc was created in order to eliminate sub-registries of births and the need to collect data on the health of newborns and maternal characteristics.⁽¹⁷⁾

Several investments were made by the Ministry of Health with the purpose of improving the quality of SIM and Sinasc.⁽¹⁸⁾ Although there are still differences between the regions of the country, there is no doubt that there is an improvement in the coverage, consistency and completeness of the information observed in these systems.⁽¹⁴⁾ Some aspects such as completeness and agreement of variables need to be investigated to measure the quality of vital statistics.⁽¹⁹⁾ Linkage enables the gain of information and identifies possible errors capable of modifying health indicators, such as the incorrect filling of the fields in the forms.^(20,21)

A set of strategies to improve the adequacy of vital statistics can be used, especially: the incorporation of the active search of events in the routine of the municipalities, improvement of death surveillance, verbal autopsy in distant locations, integration with committees prevention of maternal, fetal and child deaths and the training of those involved in the production of information.⁽²²⁾

The use of linkage consists of the relationship of two or more databases that have variables in common, thus allowing the identification of records of the same individual in two or more data sources.⁽²³⁾ This technique is increasingly used in health studies because it enables the improvement of information quality, presenting low operational cost and ease of execution.⁽²⁴⁾ Through the use of database relationships, it is possible to structure a more consistent and complete database with more reliable information and thus improve information on live births and infant deaths, contributing to the planning and development of public actions more assertive. The linkage of infant births and deaths allows the use of many variables on maternal and infant characteristics to perform more detailed analyzes of infant mortality that are useful to understand the basic pattern of occurrence and its relationships. Reliable and timely infant birth and death statistics are essential for policy formulation, appropriate interventions and resource allocation to address the priority challenges of maternal and child health. In addition, the relationship of Sinasc and SIM databases provides an opportunity to measure exposures that occur before birth in fetal and infant outcomes. This study aimed to assess the quality of data (agreement and completeness) on infant deaths in the Mortality Information System and the Information System on Live Births, Recife, Pernambuco, Brazil.

Methods

This is a cross-sectional descriptive study, in which the infant death records of residents in Recife (PE), in the SIM and Sinasc banks, were assessed. Recife has a territorial extension of 219,423 km², totally urban and, administratively, it is divided in 94 districts and eight sanitary districts. In the year 2016 the estimated population for the city was 1,625,584 inhabitants.⁽²⁵⁾ Registered infant deaths from January 1, 2013, to December 31, 2016, and live births from January 1, 2012 (possibility to redeem all CLB from deaths occurred in 2013) as of December 31, 2016, were included in the study. The R Project for Statistical Computing ver-

sion 3.5.0 program was used to link the SIM and Sinasc databases. Prior to the start of the database relationship process, standardization and “clean-up” were performed in the databases. The term “newborn from” (RN from) was deleted in the field, as well as the correction of existing abbreviations for names and verification of double spaces. Standardization was also made for the mother’s name. To avoid doubts about the perfect pair, some variables that could be confounding factors were verified, such as twin newborns, duplicate records, errors in filling vital fields such as: mother’s name, gender, date of birth, and date of birth. The information contained in the CLB was considered as a gold standard when there were divergences or lack of information in the DC.

The deterministic linkage technique was applied and the CLB number was used as the key variable, since it is unique for each live birth and has a specific field for its filling in the DC. After the linkage, the variables “mother’s name”, “sex” and “date of birth” were verified for confirmation of true pairs, doubtful pairs, and non-pairs. A manual review of non-live birth-related DCs was done, and the ones that were doubly checked for pairs were added using as criteria the fields mother’s name, sex and date of birth. The date of birth was of fundamental importance in the inclusion of the key, especially in the longer studies, when there is the possibility of more than one birth in the studied period. The manual relationship of death and the alive variables allowed to complete the missing variables for describe the characteristics of the deaths. The percentage of linked deaths was calculated after the linkage according to the number of pairs correctly linked to the respective birth. In order to analyze the incompleteness of variables were defined as the percentage of unfilled fields, these being the blank fields and the fields with the code 9 (ignored). The mean of the percentage of incompleteness of each variable. The incompleteness assess the number of fields not filled in each variable (ignored + blank) and was analyzed before and after the linkage. The following criteria were used to classify incompleteness: excellent (<5%); good (5 to 9.9%); regular

(10 to 19.9%); poor (20 to 49.9%) and very bad ($\geq 50\%$).⁽²⁶⁾

The agreement verifies that the filling of a certain variable was done identically in both databases. For this analysis, the variables were divided into two types: the qualitative ones (mother’s education, length of pregnancy, type of pregnancy, type of delivery, sex of the child, date of birth of the child, number of live born children and number of stillbirths) were analyzed by the Kappa index and the quantitative variables (mother’s age and birth weight) by the Intraclass Correlation Coefficient (ICC). The Kappa index this is a statistical method for assessing the level of agreement or reproducibility between two sets of data. The ICC is a reliability index widely used in test-retest, intra-examiner and inter-indicator reliability analyzes.

The parameters used as the reference to classify the Kappa index and the ICC were: excellent agreement (0.80 to 1.00), substantial (0.60 to 0.79), moderate (0.40 to 0.59), reasonable (0.20 to 0.39), poor (0 to 0.19) and without agreement (<0). The level of significance was 5%, so the confidence intervals are constructed with 95% confidence.⁽²⁷⁾ The calculations were also performed in R program version 3.5.0.

The research was approved by the Research Ethics Committee of the Joaquim Nabuco Foundation (CAAE: 90160818.7.0000.5619).

Results

There were 114,424 live births in Sinasc between 2012 and 2016 and 1,071 infant deaths in the SIM, between the years of 2013 and 2016. In the first step of the linkage, it was possible to match 978 (91.31%) DC with their respective CLB. Subsequently, a manual search was performed on non-linked DCs and 57 pairs (5.32%) were retrieved. Thus, 1,035 perfect pairs (DC/CLB) were found, resulting in a linkage rate of 96.64% (Figure 1).

All ten variables studied presented a percentage of incompleteness of less than 5% in both SIM and Sinasc, being classified as excellent (pre- and post-linkage). In the pre-linkage analysis, the SIM

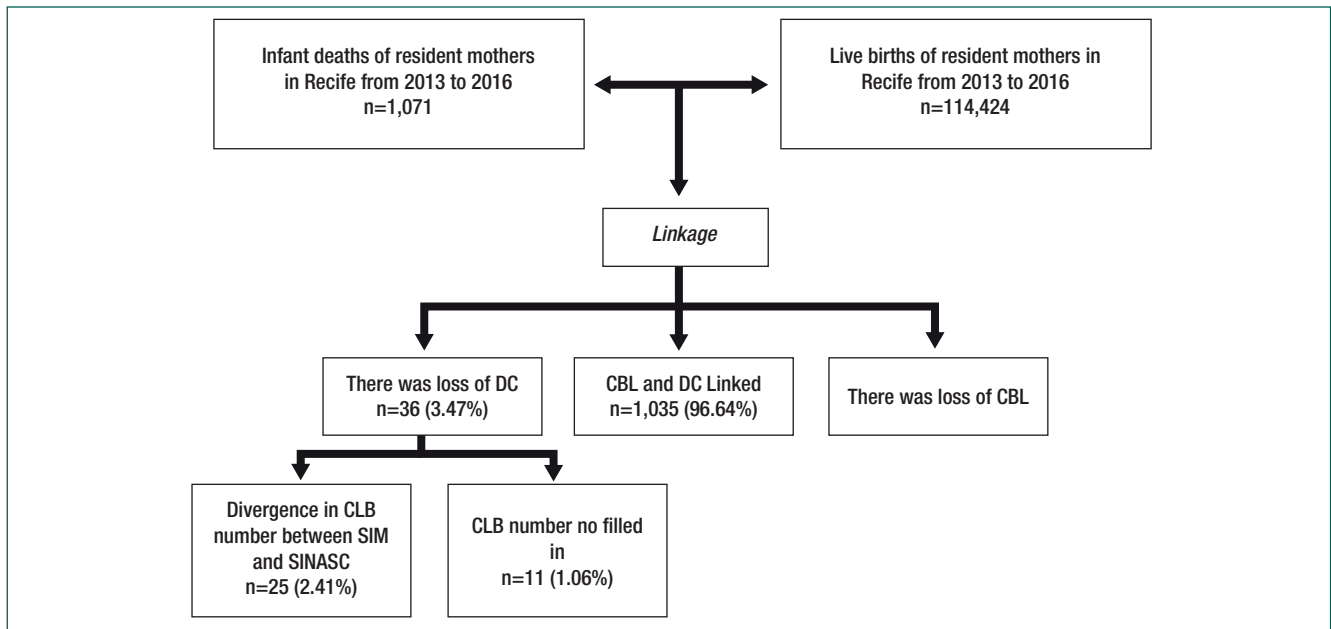


Figure 1. Flowchart of the linkage of infant deaths with registries between Sinasc and SIM

bank had the variable 'sex' as the only one that presented 100% complete filling; the variable with the highest percentage of incompleteness was 'number of stillbirths' (2.89%), followed by 'length of pregnancy' (2.67%). At Sinasc, the variables 'date of birth', 'sex' and 'mother's age' were 100% complete; the variable 'length of pregnancy' had the greatest incompleteness (1.55%), followed by 'mother's education' (1.15%) (Table 1).

In the post-linkage, the variables 'date of birth', 'sex', 'mother's age' and 'birth weight' had 100% filling; the variables 'mother's education' and 'length of pregnancy' had the highest percentage of incompleteness (0.48% each) (Table 1).

Table 1. Incompleteness (%) of the variables of infant deaths in Sinasc and SIM, pre- and post-linkage

Variables	Pre-linkage				Post-linkage	
	SIM		Sinasc		SIM+Sinasc	
	n(%)	Score	n(%)	Score	n(%)	Score
Date of birth	8(0.77)	E	-(-)	E	-(-)	E
Qualitative variables						
Mother's education	18(1.73)	E	12(1.15)	E	5(0.48)	E
Length of pregnancy	27(2.67)	E	16(1.55)	E	5(0.48)	E
Type of pregnancy	15(1.44)	E	1(0.09)	E	1(0.09)	E
Sex	-(-)	E	-(-)	E	-(-)	E
Type of delivery	17(1.64)	E	1(0.09)	E	1(0.09)	E
Quantitative variables						
Mother's age	13(1.25)	E	-(-)	E	-(-)	E
Weight at birth	13(1.25)	E	-(-)	E	-(-)	E
Number of stillbirths	30(2.89)	E	1(0.09)	E	1(0.09)	E
Number of live born children	22(2.12)	E	1(0.09)	E	1(0.09)	E

*E - Excellent (<5%); B - good (5 to 9%); RE-regular (10 to 19.9%); Bad (20 to 49.9%) and Very bad (≥ 50%)

Regarding the agreement of the variables, all had almost perfect classification; the highest agreement was the 'date of birth' variable (ICC = 0.988). The quantitative variables the totality presented excellent agreement. 'Birth weight' was the variable with the highest agreement (ICC = 0.983), followed by 'mother's age' (ICC = 0.981) (Table 2).

Table 2. Analysis of agreement between the common variables of infant deaths in Sinasc

Variables	Coefficient	L.L.	U.L.
Qualitative variables¹			
Mother's education	0.866	0.838	0.893
Length of pregnancy	0.813	0.785	0.842
Type of pregnancy	0.951	0.917	0.985
Type of delivery	0.967	0.951	0.982
Sex	0.970	0.955	0.984
Date of birth	0.988	0.982	0.995
Quantitative variables²			
Number of live born children	0.875	0.777	0.953
Number of stillbirths	0.934	0.873	0.978
Mother's age	0.981	0.971	0.989
Weight at birth	0.983	0.980	0.986

¹ Kappa coefficient; ² Intraclass correlation coefficient; L.L. - Lower limit of the 95% confidence interval; U.L. - Upper limit of the 95% confidence interval

Discussion

The linkage between the bases of the SIM and Sinasc obtained a percentage of linked infant deaths of 96.6%. All the studied variables presented a percentage of successful incompleteness in SIM and Sinasc, before and after linkage. All the analyzed

variables presented almost perfect agreement. These suggest a good quality (completeness and agreement) of SIM and Sinasc information in Recife.

Recent studies have shown that the linkage rate in Recife has remained above 95%, indicating the good quality of the systems.^(23,24) The comparison of the percentage of infant deaths linked with Sinasc among the capitals of Brazil showed that in Recife more than 97% of the registries are linked, standing out among the highest percentages of linkage success in the country.⁽²⁴⁾

In this study, it was decided to use deterministic linkage, considering the presence of the unique identifier (CLB number) found in both databases and the quality of the data analyzed. Theoretically, probabilistic linkage provides a truer capture in relation to deterministic linkages.⁽²⁸⁾ However, the probabilistic linkage involves a more complicated and time-consuming algorithm than deterministic.⁽²⁹⁾ Research comparing probabilistic and deterministic methods found that the former was more accurate with poorer quality data, while the latter was equally valid and faster in high quality data.⁽²⁸⁾ In Brazil, a study that compared the percentage of associated registries between SIM and Sinasc, observed a predominance of the deterministic method in 22 capitals of the country.⁽²⁴⁾

Regarding the analysis of incompleteness, it was verified that all SIM and Sinasc variables were classified as excellent (less than 5% incompleteness). The evaluation of the coverage, regularity and quality of the SIM and Sinasc information showed that there was improvement throughout the country, with emphasis on the North and Northeast Regions.⁽²²⁾ Sinasc has progressed considerably, birth coverage is over 90% in the country, and the completeness of variables above 97% for hospital births demonstrates the quality and importance of information from this system for maternal and infant health policies.⁽³⁰⁾ Likewise, SIM has been showing significant evolution in the quality of the information, although the variability among regions persists and problems in the completeness of the variables.^(24,31)

In SIM, the variables with the highest percentage of incompleteness were 'number of stillbirths' and 'length of pregnancy', however, were the ones that had the greatest gain of information after the linkage. The variable 'number of stillbirths' usually

presents a high proportion of incompleteness, but when filled, has high reliability. The lack of clarity of this variable in the forms and filling instructions raises doubts, such as: whether or not to include abortions and the count of previous children. This is reflected in filling errors and possibly contributes to their incompleteness.⁽³²⁾ A study that assessed the incompleteness of neonatal deaths, identified problems in filling the variables related to reproductive history, with errors that were systematically repeated, such as the inclusion of the current stillborn as a live birth or previous deceased.⁽³³⁾

The length of pregnancy is one of the most important factors for the survival and subsequent health of the child, besides being essential for the classification of fetal death.⁽³⁴⁾ The variable 'length of pregnancy' was pointed out in another study as the one of worse filling between the variables related to pregnancy and delivery; this is able to mask facts about the care provided to the pregnant woman and the newborn, failing to inform variables predictive of the risk for infant death.⁽³⁵⁾

At Sinasc, the variables 'length of pregnancy' and 'mother's education' had the highest percentage of incompleteness. Recent evaluation of the filling of the variable 'mother's education' in the declarations of live births in the capitals of Brazil, identified a trend of improvement in its filling and attributed this improvement to the training of professionals responsible for filling and processing data and better access to information systems.⁽³⁶⁾ Specifically for Recife, the coefficient of incompleteness increased from 33.4 (1996) to 2.8 per thousand live births (2011), a reduction of 91.6%, demonstrating an unequivocal progress in the completeness of the variable.⁽³⁶⁾

The incompleteness of the variable "length of pregnancy" found in both systems may be related to some factors, among them the lack of information on the part of the woman's companion and the lack of information in the medical records.⁽³⁴⁾

In post-linkage the variables 'date of birth', 'mother's age' and 'birth weight' had the full fill, which shows the gain of previously ignored/blank fields through Sinasc for the SIM. All variables of the DC and CLB are considered mandatory, however, it is not possible to enter a CLB in the Sinasc without filling in the variables gender, weight, name and age of the mother.

This fact contributed to the fact that these variables had 100%. The availability of information in the hospital records or in the pregnant woman's card contributes to the improvement of the completeness of the variables in the CLB, since their filling occurs near the delivery and this facilitates the retrieval of unknown information by the woman's companion.⁽³⁶⁾

In the agreement analysis, the qualitative variables had almost perfect classification and the quantitative ones had excellent classification. Some factors contributed to the evolution of the quality of SIM and Sinasc variables in Recife, investments in professional training for those involved in information production, training to fill out instruments and strengthening of death surveillance.^(23,37) With more than 10 years of implementation in Recife, the strategy of infant death surveillance has as one of its purposes to improve the quality of information systems and has been shown as a differential for the qualification of vital statistics information.⁽³⁷⁾ A research that analyzed the agreement of the basic cause and the avoidability of infant deaths after the investigation of death surveillance showed a redefinition of most of the basic causes, indicating the contribution of this strategy to the improvement of the information.⁽³⁸⁾

The limitations of the study consist in not linking all records due to the problems already identified by other studies (divergence in the mother's name between CLB and DC and absence of CLB number in DC).⁽³⁹⁻⁴¹⁾ Other limitations of the study concern potential confounders that could compromise the identification of true pairs, such as duplicity of registration, twinning, spelling errors in the mother's name. However, even with problems in registering the variables, the linkage of the SIM and Sinasc databases provides information relevant to the analysis of the infant mortality profile and can be used for research and for managers to plan maternal and child care actions. It is important to understand the quality of the connection and the potential bias that can be introduced in the results of the linked data analyzes. In this study, the rate of binding was comparable with previous literature. However, it should be emphasized that the evaluation of the quality of information on infant deaths is fundamental for the continuous improvement of the SIM and Sinasc and for proposing measures to reduce infant mortality.

Conclusion

Despite advances in the quality of SIM and Sinasc, there were still problems of completeness of variables, especially in SIM. The linkage contributed to the improvement of information for the analysis of infant deaths by health services and for research. It is a technique that is easy to access and low operational cost, which can be included in the routine of infant mortality surveillance for the continuous improvement of information.

Collaborations

Romanguera AA, and Bonfim CV contributed to the study conception, data analysis and interpretation, writing of the manuscript, critical review of its intellectual content and final approval of the version to be published. Guimarães ALS, Oliveira CM and Cardoso MD contributed to data analysis and interpretation, writing of the manuscript and final approval of the version to be published.

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