Evaluation of the birth certificates as source of information on birth defects

Avaliação das declarações de nascido vivo como fonte de informação sobre defeitos congênitos

Abstract

Objective: To obtain the prevalence of birth defects in a live birth cohort, linking the live birth information system (SINASC) and the mortality information system (SIM) databases. **Methods**: Descriptive study to assess linked databases of hospital live births (LB) and neonatal deaths of resident mothers that occurred in the city of São Paulo, between January 1st, 2006 and June 30th, 2006. **Results:** According to the SINASC, the most prevalent birth defects (BD) were: BD and musculoskeletal system deformity (44.7%), nervous system BD (10.0%) and chromosomal anomalies (8.6%). There was 80.0% of recovery of circulatory system BD, 73.3% of respiratory system BD and 62.5% of digestive system BD in the linked database. Linked data set identified BD in 640 live births; the SINASC accounted for 55.2% of notifications and the SIM for 44.8%. The prevalence rate of BD based on SINASC data was 75.4%00 LB. This rate showed an increase of 14.3% when obtained from the linked dataset (86.2%00 LB). **Conclusion**: Linkage of the live birth (SINASC) and mortality systems (SIM) provides a more real BD profile. BDs notified by the SINASC were more visible at birth, while the SIM notified more fatal BD, showing the importance of utilizing both data sources.

Keywords: Birth defects; Linkage; Birth certificate; Death certificate; Information system; Prevalence.

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Resumo

Objetivo: Estimar a prevalência de defeitos congênitos (DC) em uma coorte de nascidos vivos (NV) vinculando-se os bancos de dados do Sistema de Informação de Mortalidade (SIM) e do Sistema de Informação sobre Nascidos Vivos (SINASC). **Métodos**: Estudo descritivo para avaliar as declarações de nascido vivo como fonte de informação sobre DC. A população de estudo é uma coorte de NV hospitalares do 1º semestre de 2006 de mães residentes e ocorridos no Município de São Paulo no período de 01/01/2006 a 30/06/2006, obtida por meio da vinculação dos bancos de dados das declarações de nascido vivo e óbitos neonatais provenientes da coorte. **Resultados**: Os DC mais prevalentes segundo o SINASC foram: malformações congênitas (MC) e deformidades do aparelho osteomuscular (44,7%), MC do sistema nervoso (10,0%) e anomalias cromossômicas (8,6%). Após a vinculação, houve uma recuperação de 80,0% de indivíduos portadores de DC do aparelho circulatório, 73,3% de DC do aparelho respiratório e 62,5% de DC do aparelho digestivo. O SINASC fez 55,2% das notificações de DC e o SIM notificou 44,8%, mostrando-se importante para a recuperação de informações de DC. Segundo o SINASC, a taxa de prevalência de DC na coorte foi de 75,4%₀₀ NV; com os dados vinculados com o SIM, essa taxa passou para 86,2%₀₀ NV. **Conclusões**: A complementação de dados obtida pela vinculação SIM/SINASC fornece um perfil mais real da prevalência de DC do que aquele registrado pelo SINASC, que identifica os DC mais visíveis, enquanto o SIM identifica os mais letais, mostrando a importância do uso conjunto das duas fontes de dados.

Palavras-chave: Defeitos congênitos. *Linkage*. Declaração de Nascido Vivo. Declaração de Óbito. Sistema de informação. Prevalência.

INTRODUCTION

Birth defects (BD) include all structural defects present at birth, which can be classified as primary defects, secondary defects and malformations.[1] BDs can be defined as functional or structural anomalies in fetus development, resulting from a factor originated before birth, whether genetic, environmental or unknown, present at birth or possibly manifesting itself years later, as certain chronic degenerative diseases. They can manifest as isolated forms (when the newborn (NB) shows only one defect, involving isolated body systems) or associated (when multiple defects coexist, involving many organs).[2, 3]

Causes associated with BD are still uncertain. It is estimated that between 15% and 25% are due to genetic alterations, between 8% and 12% due to environmental factors, and between 20% and 25% due to both. However, the majority (between 40% and 60%) have an unknown origin.[2, 3, 4, 5, 6]

Birth defects are an important cause of child mortality in several countries, morbidity in childhood and long-term incapacitation in developed countries. In addition, they significantly contribute to embryonic and fetal death, they are among the causes that lead to loss of potential years of life, and they are also responsible for three quarters of the population's physical handicaps.[7,8,9]

As the child mortality rate from infectious, parasitic and respiratory diseases decreased, there was an increase in BD's relative participation in child deaths. This is because, as other causes of death are controlled, BDs begin to play a proportionately more important role. However, progress in health care and basic sanitation has led to a reduction in infectious and malnourishment diseases, and, for this reason, BDs now have a greater influence on perinatal mortality.[2, 5, 10, 11,12]

Even though the number of deaths in this age group resulting from several diseases has declined in the last years in Brazil, the same is not true when it comes to BDs, which are currently the second cause of

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child mortality in this country. Among these BDs, cardiovascular and nervous system defects stand out, only falling below perinatal diseases.[7, 8, 19]

BDs are the main cause of death in the first year of life and the fifth cause of loss of potential years of life in the United States.[7] The proportion of deaths due to BD showed an increase from 14% to 22% between 1968 and 1995.[8]

Brazil does not have a specific information system on population-based BDs to monitor their prevalence. Until the 1990's, the only information available on BD frequency and distribution in the population came from mortality information system. The introduction of the variable "presence of birth defect" in the Live Birth Certificate (field 34) occurred in 1999.[8] Therefore, the *SINASC* (Live Birth Information System) can be an important instrument to monitor the BD population and, for this reason, "efforts must be made to guarantee better information gathering".[14]

Database linkage technique, by enabling the identification of the same individual in two or more databases, allows for the retrieval of information and, as a result, for an estimate closer to the real BD prevalence in live births to be obtained. The information available in *SINASC* will be complemented with *SIM* (Mortality Information System) information, by employing this technique. The most visible BDs are probably recorded in the Live Birth Certificate (BC), whereas in the Death Certificate (DC) are the most severe BDs. In this study, both the BDs recorded as underlying cause and those recorded as associated cause of death were considered.

METHODOLOGY

A descriptive study was performed in the city of São Paulo, between January 1st 2006 and June 30th, 2006. The study population was a hospital live birth cohort from mothers who live in the city of São Paulo, and the neonatal deaths were originated from this cohort.

Linked database information on live birth (BC) and neonatal death certificates (DC) for the state of São Paulo was provided by the *SEADE* (State Data Analysis System) Foundation Vital Statistics System, corresponding to 316,109 live births , where 3,004 neonatal deaths occurred.

Live newborns whose mothers did not live in the city of São Paulo (N= 226,594) were excluded from this study, resulting in 89,515 resident live newborns. Of these, non-hospital births (N= 589) and births of residents that did not occur in the city of São Paulo (N= 4,080) were also excluded, resulting in a cohort of 84,846 live birth certificates. . The database provided was linked through the deterministic method and came from the research study "Assessment of quality of information on perinatal mortality in the city of São Paulo".

The variable recorded in Field 34 of the live birth certificate – "birth defect and/or chromosomal anomaly detected: yes and no" was used. The *SEADE* Foundation codifies the birth defects recorded in the BCs and the causes of death in the DCs in accordance with the ICD-10 (International Classification of Diseases, 10th revision). BCs and DCs that showed Q00 to Q99 codes, corresponding to birth defects, were selected.

For the cohort survivors, BCs were the only source of information. For the cohort neonatal deaths, the following were used: a) BC (presence of BD in field 34) and b) DC – underlying causes and associated causes of death that were coded as BD.

The first stage was to assess how field 34 in the BC was filled in. The proportion of BCs with no record of BD was obtained. BD prevalence rates were calculated for neonatal deaths and survivors, according to information recorded in the *SINASC*.

The database was made available on Microsoft's® Windows Access and the analyses were performed using the Epi-Info® 2000 statistical package, version 3.4.1, from July 2007, and the Open Source Epidemiologic Statistics for Public Health, version 2.2.1 (http://www.openepi.com).

In accordance with the resolution n°

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196 from October 10th, 1996 (National Health Council – Human Research Regulating Norms and Directives), this project was approved by the *COEP* (Research and Ethics Committee) of the São Paulo University School of Public Health.

RESULTS

A total of 73,944 (87.2%) live births, from the cohort of the 1st semester of 2006 for the city of São Paulo, had field 34 of the BC filled in (yes and no), while 10,902 (12.8%) ignored this field or left it blank (not filled in).

A total of 640 LBs (0.8%) had a BD recorded in the BC, according to the *SINASC*. Of these, 112 (15.2%) died and 528 (0.6%) survived. The BD prevalence rate in the cohort was 75.4/10,000 LBs. The prevalence rates among survivors and neonatal deaths were 62.2/10,000 and 13.2/10,000 LBs, respectively (Table 1).

Of all the BDs recorded in BCs, the most prevalent were the following: BD and musculoskeletal system defects (44.7%), as well as in deaths and survivors, followed by nervous system BDs (10.0%   as in neonatal deaths) and chromosomal anomalies not classified elsewhere (8.6%) (Table 2). The most prevalent BDs among neonatal deaths were as follows: BD and musculoskeletal system defects (31.3%), followed by nervous system BDs (24.1%) and circulatory system BDs (10.7%). Among survivors, the most prevalent BDs were also BD and musculoskeletal system defects (47.5%), followed by chromosomal anomalies not classified

elsewhere (9.7%) and cleft lip and cleft palate (9.5%). Of all the 640 BD records in the *SINASC*, only one newborn showed three BDs: Q391 Q435 Q530; the codes Q391 and Q435 belong to the "other digestive system birth defects" group, while Q530 belongs to the "reproductive system BDs", according to the ICD-10.

Of all the 736 cohort neonatal deaths had 183 BDs recorded in the *SIM*, representing 24.9% of all deaths, and it represented the second most important cause of death in the cohort studied. Of all the 183 BD deaths recorded in the cohort, 144 (78.7%) were the underlying cause of death and 39 (21.3%) were an associated cause of death. Among the 144 BDs recorded as the underlying cause of death, there was a higher frequency of deaths with BDs classified as: circulatory system BDs (32.6%), respiratory system BDs (18.8%), nervous system BDs (15.3%) and BD and musculoskeletal system defects (8.3%).

The order of causes of death from BDs, recorded as associated causes, was different from those observed in the group of BDs as underlying cause. Among the 39 records of death from BDs as associated cause of death, the most frequent were the following: nervous system BD (30.8%), circulatory system BD (25.6%) and respiratory system BD and other BDs (18% each). Of all the BDs recorded as associated causes of death, eight showed two types of BDs and one newborn showed three types of BD. All newborns with recorded BD as associated cause of death also had a record of BD as the underlying cause of death (39 NBs).

Table 1 – Number of neonatal deaths, survivors and live births with birth defects, according to *SINASC* data. City of São Paulo, 1st semester of 2006.

Defeito Congênito	Óbitos			Sobreviventes			Nascidos Vivos		
	N	%	Prev.*	N	%	Prev.*	N	%	Prev.*
Com DC	112	15,2	13,2	528	0,6	62,2	640	0,8	75,4
Sem DC	624	84,8	..	83582	99,4	..	84206	99,2	..
TOTAL	736	100,0	..	84110	100,0	..	84846	100,0	..

Source: *Fundação SEADE – Sistema Estadual de Análises de Dados* (*SEADE* Foundation – State Data Analysis System).
Note: *: Prevalence rate per 10,000 LBs.

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Table 2 – Number, percentage and prevalence rate* of birth defects recorded in the *SINASC* for deaths, survivors and live births of the cohort. City of São Paulo, 1st semester of 2006.

Grupamento segundo a CID-10		Óbitos			Sobreviventes			Total		
		N	%	Prev.*	N	%	Prev.*	N	%	Prev.*
MC sist. nervoso	(Q00- Q07)	27	24,1	3,2	37	7,0	4,4	64	10,0	7,5
MC olho,ouvido,face,pescoço	(Q10-Q18)	1	0,9	0,1	20	3,8	2,42,4	21	3,3	2,5
MC ap. circulatório	(Q20-Q28)	12	10,7	1,4	28	5,3	3,3	40	6,3	4,7
MC ap. respiratório	(Q30-Q34)	4	3,6	0,5	2	0,4	0,2	6	0,9	0,7
Fenda labial e fenda palatina	(Q35-Q37)	3	2,7	0,4	50	9,5	5,9	53	8,3	6,3
Outras MC ap. digestivo	(Q38-Q45)	3	2,7	0,4	20	3,8	2,4	23	3,6	2,7
MC órgãos genitais	(Q50-Q56)	5	4,5	0,6	39	7,4	4,6	44	6,9	5,2
MC ap. urinário	(Q60-Q64)	7	6,3	0,8	9	1,7	1,1	16	2,5	1,9
MC e deform. ap. osteomusc	(Q65-Q79)	35	31,3	4,1	251	47,5	29,6	286	44,7	33,7
Outras MC	(Q80-Q89)	11	9,8	1,3	21	4,0	2,5	32	5,0	3,8
A. crom.não clas. outra parte	(Q90-Q99)	4	3,6	0,5	51	9,7	6,0	55	8,6	6,5
TOTAL		112	100,0	13,2	528	100,0	62,2	640	100,0	75,4

Source: *Fundação SEADE – Sistema Estadual de Análises de Dados* (*SEADE* Foundation – State Data Analysis System).
Note: *: Prevalence rate per 10,000 LBs.

The use of *SIM* and *SINASC* data enabled the identification of a total of 731 newborns with BDs, of which 548 (75%) were only recorded in the BC, 92 (12.6%) in the BC and DC, and 91 (12.4%) in the DC exclusively. As regards all the newborns with BDs in the cohort, which were 640 initially, 91 NBs were added with this procedure, and there were 731 newborns with BDs. The correction obtained by using the linkage technique was 14.3% (91/640) (Table 3).

A total of 55.2% of BD notifications were recorded by the *SINASC*, while 44.8% were recorded by the *SIM*, i.e. the *SIM* was found to be a very important information system to retrieve BD data in the cohort.

According to the *SINASC*, the BD prevalence rate of the hospital live birth cohort in the 1st semester of 2006, in the city of São Paulo, was 75.4/10,000 LBs. The prevalence rate, with data corrected by the *SIM*, was 86.2/10,000 LBs, that is, data retrieval with *SIM* increased BD prevalence in the cohort by 14.3% (Table 4).

Of all the 92 deaths with information on BDs in the BC and DC, 41 belonged to the same group, according to the ICD-10, and 51 belonged to different groups, as shown on Table 5. The following BDs, belonging to the same group, according to the ICD-10, were recorded in the two most prevalent sources of information: nervous system BDs (46.3%), circulatory system and musculoskeletal system BDs (17.1% each), and other BDs (7.3%).

Of all the BDs belonging to distinct groups, there was a higher frequency of newborns with BDs and musculoskeletal system defects in the *SINASC* (N=18). Among these newborns, 8 (44.4%) had respiratory system BDs, 5 (27.8%) had other BDs and 3 (16.7%) had other digestive system BDs recorded in the *SIM*. A total of seven NBs with urinary system BD in the *SINASC* had respiratory system BDs in the death certificate (*SIM*).

Of all the seven NBs with records of nervous system BDs at birth, 4 (57.0%) had other BDs, 2 (28.6%) had urinary system BDs and 1 (14.3%) had BD and musculoskeletal system defects in the *SIM*.

These data show a newborn who had one type of BD at birth, but died from another type of BD. Thus, it is more difficult to identify multiple BDs with information from *SINASC*. However, when this is linked to *SIM*

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Table 3 – Number and percentage of birth defects, according to information system (*SINASC* and *SIM*). City of São Paulo, 1st semester of 2006.

Fonte	Óbitos		Sobreviventes		Total	
	N	%	N	%	N	%
Apenas DN	20	9,9	528	100,0	548	75,0
DN/DO	92	45,3	0	0,0	92	12,6
Apenas DO	91	44,8	0	0,0	91	12,4
TOTAL	203	100,0	528	100,0	731	100,0

Source: *Fundação SEADE – Sistema Estadual de Análises de Dados* (*SEADE* Foundation – State Data Analysis System).

Table 4 – Number and percentage of birth defects for neonatal deaths, survivors and total number of live births, according to source of information. City of São Paulo, 1st semester of 2006.

Fonte	Óbitos			Sobreviventes			Total		
	N	%	Prev.*	N	%	Prev.*	N	%	Prev.*
SINASC	112	15,2	13,2	528	0,6	62,2	640	0,8	75,4
SIM/SINASC	203	27,6	23,9	0	0,0	0	731	..	86,2

Source: *Fundação SEADE – Sistema Estadual de Análises de Dados* (*SEADE* Foundation – State Data Analysis System).
Note: *: Prevalence rate per 10,000 LBs.

Table 5 – Presence of birth defects in neonatal deaths recorded in the *SINASC* and *SIM*, according to ICD-10 groups. City of São Paulo, 1st semester of 2006.

DC presente no SINASC e no SIM	N	%
Pertencentes ao mesmo grupamento	41	44,6
Pertencentes a grupamento diferente	51	55,4
TOTAL	92	100,0

Source: *Fundação SEADE – Sistema Estadual de Análises de Dados* (*SEADE* Foundation – State Data Analysis System).

data, it is possible to identify individuals with multiple BDs.

Using *SIM* data, the BDs found to be more important were the respiratory system BDs (N=20); other BDs came in second (N=11); circulatory system BDs came in third (N=5); followed by BDs and musculoskeletal system defects (N=4); urinary system BDs (N=4) and chromosomal anomalies not classified elsewhere (N=2).

The most prevalent BDs recorded in the *SINASC* were as follows: BDs and musculoskeletal system defects (85.4%) and nervous system BDs (84.4%). Cleft lip and cleft palate (N=3, 100.0%) and reproductive system BDs (N=5, 100.0%) were recorded in the *SINASC* exclusively.

After linkage, there was an 80% retrieval of newborns with circulatory system BDs, 73.3% of those with respiratory system BDs and 62.5% with other digestive system defects.

Table 6 shows the prevalence rate, according to the ICD-10 group, for both sources of information individually and after data linkage. A change in the order of BDs in the cohort live births can be observed. According to *SINASC* data, BDs and muscu-

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Table 6 – Number, percentage and birth defect prevalence rate*, according to ICD-10 groups and information on cohort neonatal deaths in the *SINASC* and *SIM*. City of São Paulo, 1ˢᵗ semester of 2006.

Grupamento segundo a CID-10		SINASC			SIM			Total		
		N	%	Prev.*	N	%	Prev.*	N	%	Prev.*
MC sist. nervoso	(Q00- Q07)	27	84,4	3,2	5	15,6	0,6	32	100,0	3,8
MC olho,ouvido,face,pescoço	(Q10-Q18)	1	50,0	0,1	1	50,0	0,1	2	100,0	0,2
MC ap. circulatório	(Q20-Q28)	12	20,0	1,4	48	80,0	5,7	60	100,0	7,1
MC ap. respiratório	(Q30-Q34)	4	26,7	0,5	11	73,3	1,3	15	100,0	1,8
Fenda labial e fenda palatina	(Q35-Q37)	3	100,0	0,4	0	0,0	0,0	3	100,0	0,4
Outras MC ap. digestivo	(Q38-Q45)	3	37,5	0,4	5	62,5	0,6	8	100,0	0,9
MC órgãos genitais	(Q50-Q56)	5	100,0	0,6	0	0,0	0,0	5	100,0	0,6
MC ap. urinário	(Q60-Q64)	7	58,3	0,8	5	41,7	0,6	12	100,0	1,4
MC e deform. ap. osteomusc	(Q65-Q79)	35	85,4	4,1	6	14,6	0,7	41	100,0	4,8
Outras MC	(Q80-Q89)	11	61,1	1,3	7	38,9	0,8	18	100,0	2,1
A. crom.não clas. outra parte	(Q90-Q99)	4	57,1	0,5	3	42,9	0,4	7	100,0	0,8
TOTAL	112	52,2	13,2	91	44,8	10,7	203	100,0	23,9	

Source: *Fundação SEADE – Sistema Estadual de Análises de Dados* (*SEADE* Foundation – State Data Analysis System).
Note:*: Prevalence rate per 10,000 LBs (total: 84,846 – cohort).

loskeletal system defects occupied the first place, nervous system BDs came in second, and circulatory system BDs came in third. After data linkage, circulatory system BDs occupied the first place, with a high prevalence rate correction (407%). Respiratory system BDs showed a 160% increase in their prevalence rate; other BDs also showed high prevalence rate correction (61.5%); even the BDs which occupied the first place in the *SINASC* showed a correction of about 18.8%. These data reveal the importance of the joint use of the two sources of information.

DISCUSSION

Quality of information on BDs in the *SINASC* can be considered reasonable,[15] as lack of recorded information was 12.8% (ignored or left blank)[16], indicating that it is possible to use *SINASC* data to assess BDs. In five years, there was an improvement in quality of such recorded information in the *SINASC*, in the city of São Paulo. A study performed in the south area of the city of São Paulo showed that lack of information in field 34 (sum of those ignored and left blank) was 30.0% in 2001.[14] Then, in 2006, lack of information was 7.9%[17] in this same location. Thus, in five years, there was great data improvement. The frequency of BDs in the live birth cohort was 0.8%, according to the *SINASC*. Results from this study are in agreement with the predominance of musculoskeletal system defects, followed by the central nervous system, as found in the cities of Rio de Janeiro, Vitória and Vale do Paraíba Paulista, in Brazil, and in the city of Caracas, in Venezuela. These results are similar to those found in the United States and in Europe.[3,13,18] The prevalence of BDs in the city of São Paulo is comparable to that of the city of Rio de Janeiro, according to *SINASC* data.[13]

The higher frequency of recorded BDs belongs to the groups that are clinically perceptible at birth, whether because they are visible or because they show conditions

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incompatible with life (anencephalic new-borns: N=15). This, in its turn, indicates that the type of BD present influences its diagnosis and recording in the *SINASC* and, as a result, will have an effect on its prevalence.

Information on BDs in the *SIM* focuses on indicating the underlying cause of death (78.7%), which shows there has not been a change in the pattern of mortality from BDs for a long time, similarly to what was recorded in the state of São Paulo, in 1989.[20] In the city of Londrina, state of Paraná, deaths from BDs occurred, in a decreasing order of importance, due to: multiple defects, heart diseases, diaphragmatic hernia, polycystic kidneys and hydrocephaly.[21]

It is more difficult to identify multiple BDs when the information is based on *SINASC* data (0.1%oo LBs). However, after linkage with *SIM* data, those individuals with multiple BDs are more clearly identified (1.1%oo LBs).

Results showed that more apparent BDs are more frequently recorded in the *SINASC*, whereas the BDs present in the *SIM* are usually those less visible externally and those that cause physiological problems incompatible with life, i.e. those that lead to death. In addition, only by adding these deaths through database linkage can these BDs be obtained. This result shows the importance of using linked data from these two information systems, which provides a more realistic BD prevalence, differently from working with a single information system.

CONCLUSIONS

The *SINASC* can be used as data source to monitor birth defects in the city of São Paulo. Despite the improvement in data recording observed, it is still necessary to develop actions to help these be recorded in birth certificates. The linked *SIM* and *SINASC* databases are found to be an efficient mechanism to retrieve data, providing correction measures for BD prevalence in the population, identification of multiple BDs and a different BD distribution pattern.

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