

Epidemiology of congenital heart disease in Brazil

Epidemiologia da cardiopatia congênita no Brasil

Valdester Cavalcante Pinto Júnior¹, MD, MSc; Klébia Magalhães P. Castello Branco², PhD; Rodrigo Cardoso Cavalcante³; Waldemiro Carvalho Junior⁴, MD; José Rubens Costa Lima⁵, PhD; Sílvia Maria de Freitas⁶, PhD; Maria Nazaré de Oliveira Fraga⁷, PhD; Nayana Maria Gomes de Souza⁸

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Abstract

Introduction: Congenital heart disease is an abnormality in the structure or cardiocirculatory function, occurring from birth, even if diagnosed later. It can result in intrauterine death in childhood or in adulthood. Accounted for 6% of infant deaths in Brazil in 2007.

Objective: To estimate underreporting in the prevalence of congenital heart disease in Brazil and its subtypes.

Methods: The calculations of prevalence were performed by applying coefficients, giving them function rates for calculations of health problems. The study makes an approach between the literature and the governmental registries. It was adopted an estimate of 9: 1000 births and prevalence rates for subtypes applied to births of 2010. Estimates of births with congenital heart disease were compared with the reports to the Ministry of Health and were studied by descriptive methods with the use of rates and coefficients represented in tables.

Results: The incidence in Brazil is 25,757 new cases/year,

distributed in: North 2,758; Northeast 7,570; Southeast 10,112; South 3,329; and Midwest 1,987. In 2010, were reported to System of Live Birth Information of Ministry of Health 1,377 cases of babies with congenital heart disease, representing 5.3% of the estimated for Brazil. In the same period, the most common subtypes were: ventricular septal defect (7,498); atrial septal defect (4,693); persistent ductus arteriosus (2,490); pulmonary stenosis (1,431); tetralogy of Fallot (973); coarctation of the aorta (973); transposition of the great arteries (887); and aortic stenosis 630. The prevalence of congenital heart disease, for the year of 2009, was 675,495 children and adolescents and 552,092 adults.

Conclusion: In Brazil, there is underreporting in the prevalence of congenital heart disease, signaling the need for adjustments in the methodology of registration.

Descriptors: Heart Defects, Congenital. Epidemiology. Health Policy. Brazil.

¹Specialist in Cardiovascular Surgery. Master's Degree in Evaluation of Public Policies at Federal University of Ceará (UFC). Head of Pediatric Cardiovascular Surgery at Hospital Messejana and InCor Criança of Fortaleza, CE, Brazil. Head of the Pediatric Cardiovascular Surgery – Hospital Messejana).

²University of São Paulo. Head of Pediatric Cardiology of the Hospital Messejana Dr. Carlos Alberto Studart Gomes, Fortaleza, CE, Brazil.

³Medicine student at UniChristus, Fortaleza, CE, Brazil.

⁴Specialist in cardiovascular surgery by BSCCV. Cardiovascular Surgeon at Hospital de Messejana Dr. Carlos Alberto Studart Gomes, Fortaleza, CE, Brazil.

⁵Epidemiologist Physician of Epidemiological Surveillance Cell of Fortaleza, Municipal Health Department, CE, Brazil. Master's Degree in Public Health from Unicamp, Campinas, SP, Brazil.

⁶Professor of Master's Degree Course of Vocational Assessment of Public Policies by the UFC, Fortaleza, CE, Brazil.

⁷Professor of Professional Master's Degree Course in Public Policy Evaluation by the UFC, Fortaleza, CE, Brazil.

⁸Nurse at the Hospital de Messejana Dr. Carlos Alberto Studart Gomes, Fortaleza, CE, Brazil.

This study was carried out at Heart Institute for Children and Adolescents - InCor Criança, Fortaleza, CE, Brazil.

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Correspondence address:

Valdester Cavalcante Pinto Júnior

Rua Núbia Barrocas, 125, Parque Manibura Fortaleza - Ceará - Brazil

Zip code: 60821-775

E-mail: incorcrianca@yahoo.com.br

Abbreviations, acronyms & symbols	
AoCo	Aortic coarctation
ASD	Atrial septal defect
CHD	Congenital heart disease
MOH	Ministry of Health
PDA	Persistent ductus arteriosus
T4F	Tetralogy of Fallot
TGA	Transposition of the great arteries
VSD	Ventricular septal defect

Resumo

Introdução: Cardiopatia congênita é uma anormalidade na estrutura ou função cardiocirculatória, ocorrente desde o nascimento, mesmo que diagnosticada posteriormente. Pode resultar em morte intraútero, na infância ou na idade adulta. Foi responsável por 6% dos óbitos infantis, no Brasil, em 2007.

Objetivo: Estimar a subnotificação na prevalência das cardiopatias congênicas no Brasil e seus subtipos.

Métodos: Os cálculos das prevalências foram realizados aplicando-se coeficientes, atribuindo-lhes função de taxas para cálculos dos agravos. O estudo faz aproximação entre a literatura e os registros governamentais. Adotou-se estimativa de 9:1000

nascimentos e taxas de prevalências para subtipos, aplicadas aos nascimentos de 2010. As estimativas de nascimentos com cardiopatia congênita foram comparadas com as notificações ao Ministério da Saúde. Foram estudados por métodos descritivos com uso de taxas e coeficientes, representados em tabelas.

Resultados: A incidência, no Brasil, é de 25.757 novos casos/ano, distribuídos em: Norte 2.758; Nordeste 7.570; Sudeste 10.112; Sul 3.329; e Centro-Oeste 1.987. Em 2010, foram notificados ao SINASC/MS 1.377 casos de nascidos com cardiopatias congênicas, o que representa 5,3% do estimado para Brasil. No mesmo período, os subtipos mais frequentes foram: comunicação interventricular (7.498); comunicação interatrial (4.693); persistência do canal arterial (2.490); estenose pulmonar (1.431); tetralogia de Fallot (973); coarctação da aorta (973); transposição das grandes artérias (887); e estenose aórtica 630. A prevalência de cardiopatias congênicas, para o ano de 2009, foi 675.495 crianças e adolescentes e 552.092 adultos.

Conclusão: Há, no Brasil, subnotificação na prevalência das cardiopatias congênicas, sinalizando para a necessidade de adequações na metodologia de seu registro.

Descritores: Cardiopatias Congênicas. Epidemiologia. Política de Saúde. Brasil.

INTRODUCTION

Congenital Heart Disease (CHD) is an abnormality in the structure or cardiocirculatory function that occurs from birth, even if subsequently diagnosed^[1]. It varies in severity, occurring from communications between cavities that spontaneously regress up to major malformations that even require several procedures, surgical or catheterization. It can result in intrauterine, childhood or adulthood death^[2].

Globally, 130 million children are born each year. Of these, four million die in the neonatal period, or that is, in the first 30 days of life^[3] and 7% of the fatalities are related to CHD^[4].

In 2007, in Brazil, 6% of deaths in children under one year of age were by CHD^[5]. Among the congenital malformations, cardiovascular abnormalities are the most common cause of infant mortality, 40% under study in São Paulo/Brazil^[6] and 26.6% and 48.1% in the US^[7,8]. Delays in the development and cognitive deficits are associated with a congenital heart disease of 20% to 30%^[9-11].

Hoffman & Kaplan reported a variation in prevalence rate of 4:1000 to 50:1000 births. The highest one is related to the occurrence of low severity injuries that are solved without medical intervention^[12].

In Brazil, studies on the epidemiology of congenital heart disease with different cuts, express coefficients ranging from 5.494^[13] to 7.17 per 1,000 births^[14]. For a group with low birth weight, the prevalence rate ranged from 10.7 to 40.7:1,000 births^[15].

Amorim, in Minas Gerais, Brazil, from 1990 to 2003, analyzing data on 29,770 newborns, found prevalence rate of

congenital heart defects corresponding to 9.58:1,000 births and equal to 87.72:1,000 between stillbirths^[16]. Rivera, in Alagoas, Brazil, for the same age group, found prevalence in 13.2:1,000 births^[17].

Study review and meta-analysis on the global prevalence of congenital heart disease included 114 studies, with a study population of 24,091,867 births. The prevalence rate estimated at 9.1 per 1,000 births remains stable over the last 15 years. This corresponds to 1.35 million newborns with CHD each year^[18].

In this study, prevalence is the greatness of the event at any given time^[19], adopting the coefficient of 9:1000 births as the basis for calculation of CHD in Brazil and in each federal unit.

The scarcity of specific bibliography and reliable statistics on the Brazilian population with congenital heart disease forces the approximation to the international literature, in order to estimate the prevalence of CHD in Brazil and compare it to the official notifications, serving therefore as basis for formulation of public policies, based on more realistic data.

Objective

The aim of this study was to estimate underreporting in the prevalence of congenital heart disease in Brazil and its most frequent subtypes.

METHODS

We adopted for the test under report, the prevalence rate of congenital heart disease equal to 9:1000 births, defined in a review and meta-analysis study for births worldwide^[18].

Population and birth registries in Brazil, regions and federated

units, were obtained by consulting the Demographic Census of 2010, published in 2012, and made available on the DATASUS/Ministry of Health (MOH) website^[20].

Secondary data relating to the distribution by age group, the Brazilian population of 2009, published by the Demographic Census of 2010^[20], were divided into two groups: the first with children under 18 years of age and the second formed by adults, aged 18 and more.

Rates for the prevalence of congenital heart disease by age group, were defined in the study on the population of Canada. For children under 18, 11.89 CHD per 1,000 individuals and 4.09 CHD per 1,000 adults^[21].

The prevalence of congenital heart disease in 2010, recorded in SINASC (System of Live Birth Information), was obtained by consulting the DATASUS/MOH website.

The estimated prevalence of congenital heart disease in

Brazil, was generated when the prevalence rate equal to 9:1000 births was applied to quantitative births.

Estimated prevalence of congenital heart disease was compared with notifications from SINASC/MOH, revealing the disease registration percentage in Brazil and the federal units.

The estimated prevalence of the eight most frequent subtypes of CHD was achieved by applying to the quantitative of birth the prevalence rates per 1,000 births of each subtype, namely: Ventricular septal defect (VSD) 2.62; Atrial septal defect (ASD) 1.64; Persistent ductus arteriosus (PDA) 0.87; Pulmonary stenosis 0.5; Tetralogy of Fallot (T4F) 0.34; Aortic Coarctation (AoCo) 0.34; Transposition of the great arteries (TGA) 0.31 and Aortic Stenosis, 0.22^[18].

The CHD prevalence rates among age groups were estimated when applied to population groups their respective relative rates of prevalence^[21].

Table 1. Distribution of the number of births, prevalence of Congenital Heart Disease (CHD), birth notification with (CHD) - SINASC/Ministry of Health (MOH) and notification percentage for Brazil, regions and federated units in 2010.

Region/State	Born	Prevalence (CHD) 9:1.000 births	Notification to (CHD) SINASC/MS	% of Notification
BRAZIL	2,861,868	25,757	1,377	5.3
North	306,422	2,758	51	1.8
Rorônia	25,835	233	3	1.3
Acre	16,495	148	0	0
Amazonas	74,188	668	19	2.8
Roraima	9,738	88	3	3.4
Pará	140,687	1,266	19	1.5
Amapá	15,008	135	3	2.2
Tocantins	24,471	220	4	1.8
Northeast	841,160	7,570	162	2.1
Maranhão	119,566	1,076	14	1.3
Piauí	49,424	445	3	0.67
Ceará	128,831	1,159	31	2.7
Rio Grande do Norte	47,668	429	8	1.9
Paraíba	58,699	528	8	1.5
Pernambuco	136,591	1,229	45	3.7
Alagoas	54,164	487	13	3
Sergipe	34,016	306	8	2.6
Bahia	212,201	1,910	32	1.7
Southeast	1,123,593	10,112	837	8.3
Minas Gerais	255,126	2,296	99	4.3
Espírito Santo	51,853	467	12	2.6
Rio de Janeiro	215,262	1,937	58	3.0
São Paulo	601,352	5,412	668	12
South	369,905	3,329	277	8.3
Paraná	152,051	1,368	80	5.8
Santa Catarina	84,611	761	74	9.7
Rio Grande do Sul	133,243	1,199	123	10
Midwest	220,788	1,987	50	2.5
Mato Grosso do Sul	40,132	361	10	2.8
Mato Grosso	48,929	440	6	1.4
Goiás	87,476	787	14	1.8
Distrito Federal	44,251	398	20	5

Source: MoH/SVS/DASIS - Live Births Information System - SINASC - 2010.

The data were evaluated by descriptive methods using rates and ratios represented in tables.

RESULTS

In 2010, in Brazil, 2,861,868 births were reported. When applied the prevalence rate of congenital heart disease of 9:1,000 births, an estimate of 25,757 new cases for the year under study was found. The occurrence of CHD in the Brazilian regions, for the same year, was as follows: North 2758; Northeast 7,570; Southeast 10,112; South 3329; and Midwest 1,987 new cases Table 1.

In the same period, 1,377 cases of births with CHD were reported to the Ministry of Health/SINASC, representing 5.3% of estimated for Brazil. The distribution by federal unit is visualized in Table 1.

In this study, the prevalence for the year 2010, from the eight most frequent subtypes of CHD were: Ventricular septal defect (VSD) 7498; Atrial septal defect (ASD) 4693; Persistent ductus arteriosus (PDA) 2490; Pulmonary stenosis 1,431; Tetralogy of Fallot (T4F) 973; Aortic coarctation (CoA) 973; Transposition of the great arteries (TGA) 887 and Aortic Stenosis 630 Table 2.

In 2009, to a Brazilian population of 191,795,000, divided into 56,809,000 under 18 and 134 986 000 adults was estimated a prevalence of 675,495 children and adolescents and 552,092 adults with congenital heart disease.

DISCUSSION

Pinto Jr et al.^[22] propose, in a study on regionalization of Brazilian pediatric cardiovascular surgery, the implementation of a support network for patients with congenital heart disease, of fair range for all regions of Brazil. Therefore, it becomes important to define the prevalence and distribution of the disease and its subtypes for each territory.

The lack of national studies forces the approximation of the numbers with specific international literature and thus, through estimates, it reveals a scenario that best describes the reality.

It is common to find in the scientific literature that large differences in epidemiological calculations, which stems in part of the variation in sample selection in which the studies are performed^[12,15,16]. Studies on the prevalence of CHD after the first year of life underestimate the occurrence of the disease in the fetus and newborn, considering that 20% of children die in their first year of life^[23]. Another aspect that implies inaccuracies is related to the fact that 30% of CHD can not be diagnosed in the first weeks of life^[24].

CHD prevalence rate equal to 9:1000 births, defined in the study review and meta-analysis to births worldwide^[18], was defined as basis for calculation of CHD estimates for this study.

Thus, estimates for Brazil point to 25,757 new cases of CHD/year, distributed by regions North 2,758; Northeast 7,570; Southeast 10,112; South 3329; and Midwest 1,987.

The notifications published by DATASUS/MS have shown 1,377 births with CHD in 2010, corresponding to 5.3% of the estimate of 9:1,000 births used for this study.

Therefore, the public policies in this segment are supported by a reality of underreporting. Thus, assumptions of the Unified Health System; as universality, comprehensiveness and equity, principles of health-inducing public policies with quality^[25], remain outside of care to this group of patients.

Knowing that 25% of births with CHD require invasive treatment in the first year of life^[26], in order to meet the demand, it would be needed 6,439 procedures per year in Brazil. In 2008, however, 1919 procedures were performed^[5]. There is, therefore, for this age group, deficit of procedures is about 70%.

A quantitative explanation of congenital heart disease, its territorial distribution and classification by subtypes associated with the determination of risk for disease, allows establishing planning for the health care of this population.

Thus, considering all the variables, it is possible to direct investments equally to this group that, in 2009 amounted to 675,495 children and adolescents and 552,092 adults with CHD, with expected annual growth rate of 1% to 5%, depending on age and the distribution of^[21,27] injuries.

Table 2. Distribution of the prevalence of the eight CHD subtypes in Brazil and in the regions for the year 2010.

Region	Births	VSD 2.62*	ASD 1.64*	PDA 0.87*	Pulm. Stenosis 0.5*	T4F 0.34*	AoCo 0.34*	TGA 0.31*	Ao Stenosis 0.22*
BRAZIL	2,861,868	7,498	4,693	2,490	1,431	973	973	887	630
North	306,422	803	503	267	153	104	104	95	67
Northeast	841,160	2,204	1,380	732	421	286	286	261	185
Southeast	1,123,593	2,944	1,843	978	562	382	382	348	247
South	369,905	969	607	322	185	126	126	115	81
Midwest	220,788	578	362	192	110	75	75	68	49

Source: MoH/SVS/DASIS - Live Births Information System - SINASC - 2010. *Prevalence of types of CHD per 1,000 births. CHD=congenital heart diseases; VSD=ventricular septal defect; ASD=atrial septal defect; PDA=persistent ductus arteriosus; Pulm Stenosis=pulmonary stenosis; T4F=tetralogy of Fallot; AoCo=aortic coarctation; TGA=transposition of the great arteries; Ao Stenosis=aortic stenosis

Transposition of the gap between standards, Ordinances 1169/GM and 210/SAS-MS^[28,29] and the assistance requires political will and planning aimed at improving access to pediatric cardiovascular surgery centers, financing of Cardiology and Cardiovascular Surgery Pediatric; database feeding; promote management for quality and establish continuing education programs^[5,6].

Failure to observe these points, which are fundamental in the design and implementation of health care policy for CHD patients, blames the Brazilian system of health care, public and supplementary, to leave outside the surgical treatment of 62% of infants with congenital heart disease, reaching in some regions of Brazil to 76 and 91%^[5].

Gomes^[30], in an editorial, “the debt to the nation’s health: the case of congenital heart disease,” translates numbers into words and says:

[...] became untenable the acceptance of the quality of health care of the Brazilians. Felt by the population, but mainly affecting patients, their families, doctors and all other professionals involved, and even more so when it involves children with congenital heart disease, excluded from the basic right of adequate treatment and the chance to be alive.

Facing such problem requires the participation of civil society in the development of social policies and it is mandatory for the elaboration of issues in the social area, the intervention of agents who experience difficulties, either as carriers of disease, either as family components, either as professionals^[31].

Study limitations

The calculation of the prevalence of congenital heart disease and their most frequent subtypes was anchored in study review and meta-analysis that proposed to estimate the prevalence of this disease in the world^[18]. One of the limitations of this meta-analysis is not cover the entire world population, in addition to using only studies with summaries in English and make use of government records available online, a fact that leads to underreporting error, as demonstrated in this study. In this study we found differences in prevalence rates between the continents, ranging from 1.9 to 9.3/1000 births in Africa and Asia, respectively. The author states that data from developing countries were scarce, and studies often did not include indigenous peoples and tribes.

Records to consider the entire population of births are needed to determine the true prevalence of congenital heart disease.

CONCLUSION

In Brazil, there is underreporting in the prevalence of congenital heart disease, signaling the need for adjustments in the methodology of registration.

Authors’ roles & responsibilities

VCPJ	Coordinator of the study; planning and review of the final version; analysis and/or interpretation of the data; final approval of the study; conception and design; study writing or critical review of its contents
KMPCB RCC	Study writing or critical review of its contents; text review Data survey from IBGE; performance of surgeries and/or experiments; study writing or critical review of its contents; references
WCJ	Text review and translation into english; performance of surgeries and/or experiments; study writing or critical review of its contents
JRCL	Analysis and epidemiological calculations; analysis and/or interpretation of the data; statistical analysis; conception and design of the study
SMF	Supervisor of Master’s Degree thesis which led to this study; analysis and/or interpretation of the data
MNOF	Co-supervisor of the Master’s Degree dissertation which led to this study; analysis and/or interpretation of the data; study writing or critical review of its contents
NMGS	Data survey from IBGE and references; statistical analysis; performance of surgeries and/or experiments

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