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RESEARCH

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CLINICAL-EPIDEMIOLOGICAL CHARACTERIZATION OF CHILDREN AND ADOLESCENTS WITH CONGENITAL HEART DISEASE

Caracterização clínico-epidemiológica de crianças e adolescentes portadores de cardiopatia congênita

Caracterización clínico-epidemiológica de niños y adolescentes con cardiopatía congénita

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ABSTRACT

Objective: To analyze the clinical and epidemiological characteristics of children with congenital heart disease living in the city of Rio das Ostras referred to specialized units in the state of Rio de Janeiro. **Method**: Descriptive, cross-sectional research conducted in two hospitals in the city of Rio de Janeiro, through retrospective documentary technique through data in medical records. The collection took place between September 2018 and February 2019. **Results**: 48 medical records were analyzed, with a higher proportion among students (33.3%); male (58.3%); Regarding heart disease, there was a greater proportion of acyanotic (62.5%); highlighting interatrial communication with (14.6%); followed by interventricular communication (12.5%) and aortic coarctation (12.5%). **Conclusion**: The identification of these children in the city of Rio das Ostras and their distribution throughout the national territory are essential information for the planning and implementation of programs and public policies that meet the real demands of this population segment.
DESCRIPTORS: Cardiopathies; Thoracic surgery; Pediatric nursing; Intensive care.

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RESUMO

Objetivo: Analisar características clínico-epidemiológicas de crianças portadoras de cardiopatia congênita residentes do município de Rio das Ostras referenciadas para unidades especializadas no estado do Rio de Janeiro. **Método**: Pesquisa descritiva, transversal realizada em duas unidades hospitalares no município do Rio de Janeiro, através da técnica documental retrospectiva por meio de dados nos prontuários. A coleta ocorreu entre setembro de 2018 a fevereiro de 2019. **Resultados**: Foram analisados 48 prontuários, com maior proporção entre os escolares (33,3%); do sexo masculino (58,3%); Em relação as cardiopatias, verificou-se com maior proporção as acianóticas (62,5%); destacando a comunicação interatrial com (14,6%); seguida da comunicação interventricular (12,5%) e coarctação da aorta (12,5%). **Conclusão**: A identificação dessas crianças no município de Rio das Ostras e a distribuição destas pelo território nacional são informações imprescindíveis para o planejamento e implementação de programas e políticas públicas que atendam as reais demandas deste segmento populacional.

DESCRITORES: Cardiopatias; Cirurgia torácica; Enfermagem pediátrica; Cuidados intensivos.

RESUMEN

Objetivo: Analizar las características clínicas y epidemiológicas de los niños con cardiopatía congénita que viven en la ciudad de Rio das Ostras remitidos a unidades especializadas en el estado de Río de Janeiro. **Método**: Investigación descriptiva, transversal realizada en dos hospitales de la ciudad de Río de Janeiro, a través de una técnica documental retrospectiva a través de datos en registros médicos. La recolección se realizó entre septiembre de 2018 y febrero de 2019. **Resultados**: Se analizaron 48 registros médicos, con una mayor proporción entre los estudiantes (33.3%); hombre (58,3%); Con respecto a la enfermedad cardíaca, hubo una mayor proporción de acianóticos (62.5%); destacando la comunicación interauricular con (14,6%); seguido de comunicación interventricular (12.5%) y coartación aórtica (12.5%). **Conclusión**: La identificación de estos niños en la ciudad de Rio das Ostras y su distribución en todo el territorio nacional son información esencial para la planificación e implementación de programas y políticas públicas que satisfagan las demandas reales de este segmento de la población.

DESCRIPTORES: Cardiopatías; Cirugía torácica; Enfermería pediátrica; Cuidados intensivos.

INTRODUCTION

Congenital heart diseases (CHD) are considered one of the main causes of death in early childhood and represent 40% of all congenital malformations,[1] and are characterized by one or more anatomical defects in the heart and great vessels, whose development occurs from the embryonic period until the eighth week of gestation.[2]

Clinically, CHD can be classified as cyanotic or acyanotic and, depending on the type, the clinical manifestations will be present at birth or in more advanced stages of life. Generally, cyanotic cardiopathies manifest early and require more complex interventions, especially surgery, while acyanotic cardiopathies, when they need corrections, tend to require procedures with lower technological density.[3]

During the formation of the heart, any alteration can generate defects that vary in severity, and may or may not interfere with the circulatory system.4 According to the Ministry of Health (MH), CHD represents the third largest cause of death among neonates, with the birth of 30,000 children with heart disease in Brazil every year.[5]

Important factors surround CHD, making early diagnosis, timely treatment and, in some cases, the cure of the disease difficult, among them: large anatomical and physiological variation in malformation, which leads to plurality of diagnoses, and thus, extensive variation in the nature of surgical procedures; and, scarcity of specialized health services and professionals.[6]

Only 15 to 20% of cases have a known etiology4, however, it is inferred that CHD originates from the association between factors of genetic and environmental nature.[7] About 130 million children are born each year in the world, of these, four million die in the neonatal period, i.e., before completing one month of life, and 7% of these deaths are related to CHD.[8] A meta-analysis of the global prevalence of CHD that included 114 studies, with a population of 24,091,867 births, estimated a prevalence rate of 9.1 cases per 1,000 births, corresponding to 1.35 million newborns with CHD per year.[9]

In Brazil in 2014, there were 340,284 deaths, 4,327 of them due to congenital malformations of the circulatory system, among which 3,322 were of children under one year of age.[10] However, it is assured that these data are underestimated due to failures in assertive diagnosis.[11]

In view of the facts, CHD has been a subject widely discussed, not only because of its hemodynamic repercussions capable of impacting on the patient's survival and quality of life, but also because of what was postulated by the Ministry of Health (MH) when it approved in 2017 the National Plan for Assistance to Children with Congenital Heart Disease, which guarantees the adequate diagnosis, treatment and follow-up of this population segment in the Single Health System integrating all levels of care, with guaranteed access to these services.[1]

Given the need for epidemiological studies that contribute to the visibility of these children worldwide, their identification and characterization are also essential steps for the construction of local strategies and public policies that guarantee improvements in access to the health system in order to ensure that their real needs are met. Therefore, it is necessary to track them in the most varied Brazilian municipalities, such as Rio das Ostras, located in the coastal lowlands of the state of Rio de Janeiro, Brazil, approximately 170 km from the capital of the state of Rio de Janeiro.

Thus, the objective was to analyze clinical-epidemiological characteristics of children with congenital heart disease living in the city of Rio das Ostras referenced to specialized units in the state of Rio de Janeiro.

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METHOD

Descriptive and transversal research conducted in two hospital units in the city of Rio de Janeiro, Brazil, as they are reference units for the diagnosis and treatment of cardiovascular diseases throughout the state. The choice for these units is reserved to the fact that the city of Rio das Ostras does not have a cardiology service or professionals specialized in pediatric cardiology, being necessary to refer patients with suspicion for diagnostic confirmation and possible treatment for these specialized centers. The patients, when transferred to these units, keep the link until the end of the treatment.

In order to achieve the objective of the study, the inclusion criteria were the medical records of children and adolescents from 0 to 19 years of age with congenital heart diseases, residents of the city of Rio das Ostras, referred to the units mentioned. The records unavailable for access were excluded.

Data collection was performed in the archive service of each institution, from September 2018 to February 2019, by the retrospective documental technique, from specific forms of each institution, which make up the patient's medical record, such as: medical and nursing evolution, surgical bulletin, perfusion and anesthesia record, complementary exams sheet and outpatient follow-up. The survey occurred on sociodemographic, clinical and epidemiological variables, such as gender, age, race, prematurity, weight, diagnosis, previous treatment, type of heart disease, treatment received, among others.

To register the data collected in the medical records, an Excel® spreadsheet was elaborated covering the variables of interest for this study. The data were processed in the R Program. The proportion and the measures of central tendency were calculated. The results were presented in graphs and tables with univariate and bivariate analysis.

In compliance with the Guidelines and Regulatory Standards for Research Involving Human Beings, through Resolution No. 466/2012 of the National Health Council,[12] this project was submitted to the Comitê de Ética em Pesquisa com Seres Humanos (CEP) of the Universidade Federal Fluminense and obtained approval on April 17, 2017, with the number of CAAE 63084716.4.0000. 5243, under the report number 2,017,777. For secondary data, the use of the Free and Informed Consent Term was waived.

RESULTS

Forty-eight medical records of children with congenital heart diseases were identified, referred from the city of Rio das Ostras to specialized hospitals in the city of Rio de Janeiro, of which the highest proportion was observed in the school age group 16 (33.3%) and 28 (58.3%) males. In relation to race/color, the records showed a higher proportion among brown children 26 (54.2%) (Table 1).

Table 1 - Distribution of socio-demographic variables of children with congenital heart diseases, referenced from the city of Rio das Ostras, RJ, Brazil, 2019.

Variables		
Age	**N = 48**	**%**
Newborn	4	8,3
Student	10	20,8
Preschool	10	20,8
School	16	33,3
Adolescent	8	16,7
Sex	**N = 48**	**%**
Female	20	41,7
Male	28	58,3
Race	**N= 48**	**%**
White	11	22,9
Brown	26	54,2
Black	8	16,7
Uninformed	3	6,3
Weight (Kg)		
Minimum	2,1	
Maximum	32	
Average	11	

Source: SILVA, 2019.

In the bivariate analysis, regarding the classification of heart disease, a higher proportion was found for acyanotic patients with 30 (62.6%), being the school age group for acyanotic patients nine (18.8%) and cyanotic patients seven (14.6%), and with the lowest values for newborns for acyanotic patients three (6.3%). For sex, the highest proportion was observed between male and female for acyanotic 17 (35.4%), and 13 (27.1%), respectively.

Regarding the patient's condition at the time of diagnosis, related to the type of heart disease developed, the highest proportion was of symptomatic patients with acyanotic heart disease 19 (39.6%), followed by 12 (25%) for symptomatic patients with cyanotic heart diseases. On this aspect, the most prevalent symptomatology presented by patients was respiratory disorder with eight (16.7%), followed by severe malnutrition with two (4.2%) and deficit of weight gain and cardiovascular decompensation with one (2.1%) each. In the bivariate analysis, the treatment received with the highest proportion was surgery (50%). The other variables analyzed can be verified in (Table 2).

Table 2- Distribution of the bivariate analysis of variables related to children with congenital heart diseases, referenced from the city of Rio das Ostras, RJ, Brazil, 2019.

Variables				
Age	**Acianotics**		**Cyanotics**	
	N = 48	**%**	**N = 48**	**%**
Newborn	3	6,3	1	2,1
Infant	6	12,5	4	8,3
Preschool	6	12,5	4	8,3
School	9	18,8	7	14,6
Adolescent	6	12,5	2	4,2
Total	30	62,6	18	37,5
Sex	**Acianotics**		**Cyanotics**	
	N = 48	**%**	**N = 48**	**%**
Female	13	27,1	7	14,6
Male	17	35,4	11	22,9
Total	30	62,5	18	37,5
Condition in relation to diagnosis	**Acianotics**		**Cyanotics**	
	N = 48	**%**	**N = 48**	**%**
Asymptomatic	6	12,5	2	4,2
Symptomatic	19	39,6	12	25
Not informed	5	10,4	4	8,3
Total	30	62,5	18	37,5
Treatment Received	**Acianotics**		**Cyanotics**	
	N = 48	**%**	**N = 48**	**%**
Follow-up	12	25	4	8,3
Catheterism	7	14,6	1	2,1
Surgery	11	22,9	13	27,1
Total	30	62,5	18	37,5

Source: SILVA, 2019.

Regarding the main diagnoses of children, a higher proportion of acyanotic congenital heart diseases was observed, with emphasis on interatrial communication with seven (14.6%), followed by interventricular communication with six (12.5%), and for cyanotic congenital heart disease the transposition of the great vessels presented a higher proportion with two (4.2%). The other types of congenital heart disease can be observed in (Table 3).

Table 3 - Main diagnoses of children with congenital heart diseases, referenced from the city of Rio das Ostras, RJ, Brazil, 2019.

Variables	N = 48	%
Lung stenosis	3	6,3
Aortic stenosis	2	4,2
Interventricular communication	6	12,5
Interatrial communication	7	14,6
Aortic coarctation	6	12,5
Atrioventricular septum defect	2	4,2
Double right ventricle outflow tract	2	4,2
Tricuspid insufficiency	4	8,3
Mitral insufficiency	3	6,3
Abnormal origin of the coronary artery	1	2,1
Mitral valve prolapse	1	2,1
Transposition of large base vessels	2	4,2
Single Ventricle	1	2,1
Persistence of the ductus arteriosus	6	12,5
Tetralogy of Fallot	1	2,1
Bicuspid aortic valve	1	2,1
Total	**48**	**100**

Source: SILVA, 2019.

In the analysis of age with the treatment received, it was verified in the stratum the distribution present in all age groups except newborns (0-28 days), with a minimum value in the stratum four years and maximum 11 years. For the catheterization, the procedure was observed among the adolescents and in the other age strata with a distribution of one or three registers, but with emphasis on an outlier in the adolescent group. The surgery presented records in all age groups, with emphasis on two outliers in the adolescent stratum (Figure 1).

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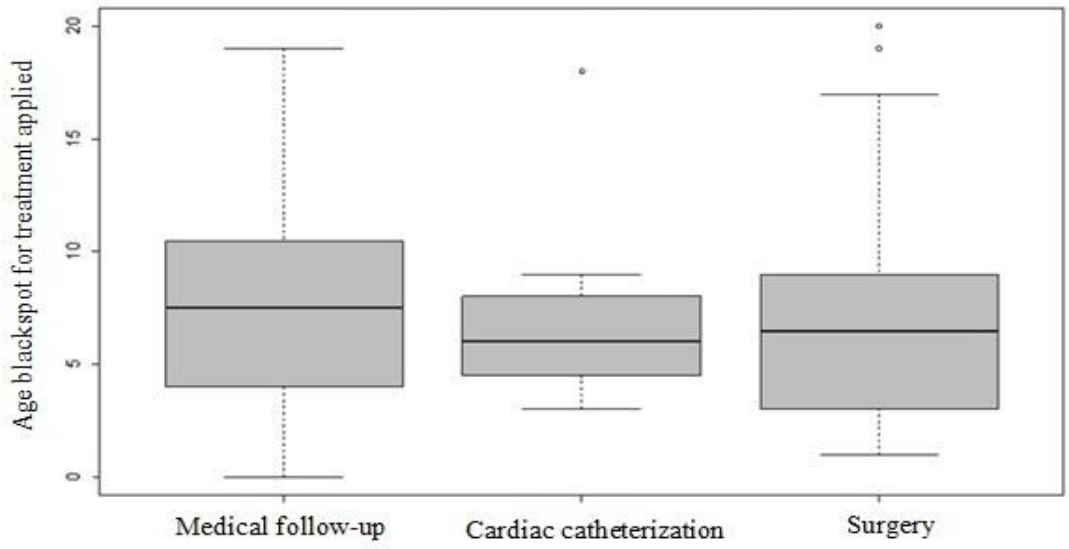
Figure 1 - Boxplot of age distribution and treatment received from children with congenital heart diseases, referenced from Rio das Ostras, RJ, Brazil, 2019.



Source: SILVA, 2019.

DISCUSSION

Among the medical records identified, the predominance of CC was observed in the school age group, followed by pre-school and infant. This finding differs from some studies, in which the age groups identified among those with congenital heart diseases were newborns.[13-14]

It is inferred that this proportion of children being referred for treatment of CHD at more advanced ages is due to the difficulty of access to the health system, considering that the municipality where they live does not have specialized services in pediatric cardiology, so little qualified professionals capable of early diagnosis of CHD. Studies developed in São Paulo and Piauí report that early diagnosis is decisive in prognosis and relevant in planning specific and individual therapeutic actions. [13-14]

Diagnosis, when early and accurate, can change the natural history of the disease and therefore the survival and quality of life of the child, because it favors proper treatment and sometimes the achievement of definitive cure in early stages of life.[15]

This local reality finds resonance in literature that reveals the great difference between developed and developing countries, such as Brazil, where access to health is deficient, leading to high mortality rates, due to inefficiency in meeting the health needs of this population group, which reinforces their programmatic vulnerability.

In relation to sex, male predominance was observed, which resembles another study on congenital valvular diseases among children.[17] In relation to ethnicity, a higher proportion was also found among brown children, as in other research developed in southern Brazil.[18]

For the clinical condition of the patient at the time of diagnosis it was observed the predominance of patients with symptoms characteristic to the development of congenital heart disease, which depending on the type can course with pulmonary hyperflow resulting in respiratory disorders, corresponding to deficit weight gain and in some cases cardiovascular decompensation.

Respiratory infections actually represent major causes of hospitalization in children with CHD, revealing the individual vulnerability of children affected by CHD due to slow immune system maturation and acute malnutrition.[18]

Another research also showed similar symptoms, among them dyspnea and heart murmur.19 However, it is recognized that many newborns with CHD do not present clinical manifestations, which decreases the chances of diagnosis, especially in regions without professionals and specialized centers.

In view of the facts, the importance of early diagnosis is reiterated[1], because besides avoiding neurological complications and aggravations, it allows the identification of probable carriers before hospital discharge, a period in which many times the symptomatology does not become apparent and cardiac auscultation may pass as normal. Besides the acyanotic congenital heart diseases, they are the most frequent, less symptomatic and more difficult to diagnose, unless they occur in association with other cardiovascular malformations, such as IVC, for example.[15]

In this directive, some public actions for the reduction of the impact caused by CHD have been outlined, with emphasis on the Neonatal Screening Program, which includes the "little heart test" by means of pulse oximetry, performed between 24 and 48 hours of life, before discharge from hospital,

associated with the clinical examination of the cardiovascular system of the newborn, which has the macro objective of identifying the heart disease before the symptoms set in, avoiding complications and death.[11] However, it is worth noting that not all Brazilian municipalities have this test on the public network, as is the case of Rio das Ostras, which further delays the diagnosis for many children.

The new surgical techniques and the early intervention, make the procedures increasingly safer allowing the total correction of many heart defects, previously considered inoperable, resulting in greater survival and better quality of life among carriers.[20]

According to evidence[7,15,20], the treatment for most of the cases is really the surgical one, being pointed out as essential for the good prognosis and survival of these children. However, in relation to this fact, it is worth noting that 49% of the services do not reach the minimum of congenital pediatric cardiac surgeries as provided in Ordinance 1,169 of June 15, 2004 which establishes the National Policy of High Complexity Cardiovascular Care. Thus, 34 services are below the recommended one, with an average of 17 surgeries/year.[21]

Regarding the type of heart disease, different epidemiological studies[1,7,16-17] found a higher proportion among acyanotic heart diseases, as revealed in this study, among them are: ventricular septal defect, interatrial communication, patent ductus arteriosus, pulmonary stenosis, aortic stenosis and aortic coarctation.

Among the cyanotic ones, the one with greater predominance was transposition of the great vessels, followed by tetralogy of fallot, anomalous drainage of the coronary artery, atrioventricular septum defect and double outflow tract of the right ventricle. These data, referring to the most frequent types of acyanotic heart diseases, partially corroborate the findings of this study, which showed the interventricular communication as the second most frequent acyanotic heart disease.

Regarding cyanotic cardiopathies, a developed study found similar data, with emphasis on the transposition of the great basic vessels as the most predominant one.[22]

Still regarding cardiopathies, this study shows proximity with another investigation regarding pulmonary and aortic stenosis, where it is highlighted that it is increasingly possible to diagnose prenatal valvular heart disease. Different studies[23-25] postulate that the diagnosis made on the fetus with aortic stenosis still in utero could change the natural course of this disease and avoid the evolution of hypoplasia of left cavities allowing a biventricular circulation in postnatal life.

The accuracy of the diagnosis of a fetal heart disease varies widely due to: the performance of echocardiography, knowledge of the cardiac anatomy and its multiple anomalies, and the technological level required. These factors influence and determine the diagnostic capacity of each center. In addition to these factors, it is also found that it is impossible to perform a complete cardiological study in all pregnancies, which has led to the identification of certain risk groups with greater probability of having a heart disease.[24]

In view of this reality, it is worth emphasizing that the Single Health System (SUS) faces numerous challenges for the care of children with congenital heart disease, among the determining factors are observed: continental dimensions of the country, unequal geographical distribution of reference centers of cardiology and pediatric cardiac surgery, absence of specialized services in more needy regions[22], such as the coastal lowlands of Rio de Janeiro.

CONCLUSION

It is concluded that the knowledge about the clinical epidemiological characteristics of children with congenital heart disease living in the city of Rio das Ostras referenced to specialized units in the city of Rio de Janeiro, allows the recognition of gaps in the local health system, envisaging the development of strategies and plans of interventions regarding the early detection and treatment of congenital heart malformation in this city.

For this, it is necessary to adopt strategies that aim at identifying and accompanying patients with CC, proposing effective assistance, culminating in early diagnosis, results of clinical and surgical assistance interventions, as well as a good prognosis bringing gains for the patient, family members and the health system, as lower expenses, better results and reduction of child morbidity and mortality are expected.

The study had as limitation the reduced number of patients with CC registered in the city of origin, a fact that made difficult the search of these in the archives of the institutions to which they are referred.

As a potentiality, this study made it possible to characterize the local reality of children with congenital heart disease under the clinical and epidemiological aspects, as a way to permeate the elaboration of care plans and interventions for prevention and early detection of this population, allowing adequate treatment and sometimes definitive cure at an early stage of life.

It is necessary to conduct new studies with a more significant sample in order to create mechanisms to measure, monitor and ultimately improve the outcomes of children with congenital heart disease in the municipality in question.

Note: The authors of this manuscript state that there is no conflict of interest.

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