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CLINICAL PROFILE AND MORTALITY OF CHILDREN WITH CONGENITAL CARDIOPATHY SUBMITTED TO SURGERY

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ABSTRACT

Objective: To make a clinical and epidemiological characterization of children with congenital heart disease submitted to cardiac surgery at a referral hospital in Paraíba and correlate these data with death. *Materials and Methods:* Quantitative, cross-sectional, retrospective study with 101 children. Categorical variables were presented in tables. To determinethe associations of dependence, the Fisher's exact Chi-Square test was used and analyses were run in the Statistical Package for the Social Sciences, adopting a significance level of 5%. *Results:* Most of the children were infants (40.6%), of the female sex (55.4%), and they were discharged in 81.2% of cases. Acyanotic heart disease (83.3%) of the Interventricular Communication type (24.8%) prevailed, and 87.1% cases had definitive surgery using Extracorporeal Circulation in 60.4%. *Discussion:* There was a significant relationship between death and type of surgery, type of heart disease, and intercurrence in the trans- and post-operative period. The most common cardiopathies that led to death were the Right Ventricle Hypoplasia and Transposition of the Large Arteries. *Conclusion:* Based on the logic of health care provided to the children with congenital heart diseases, there was a high proportion of definitive surgeries and low mortality. The guarantee of access to specialized care provides a better quality of life and a higher survival rate for these children.

INTRODUCTION

Congenital heart diseases are defined as abnormalities that affect the composition and functioning of the heart since embryonic development, persisting after birth. These changes can affect various structures of the heart, such as walls, valves and vessels, causing high morbidity and mortality and presenting a broad clinical spectrum (FROTA *et al.,* 2014). Globally, 130 million children are born per year, but up to 4 million die within the first 30 days of life, and 7% of these deaths are related to heart disease. In the latter case, changes in the functioning and hemodynamics of the heart are the most common cause of infant mortality, when speaking of congenital malformations. These data are of great concern, bearing in mind that congenital heart defects of 20 to 30% are associated with delayed growth and development leading to

intellectual deficits (ZUPAN; AAHMAN, 2005) (LAWN *et al.,* 2005) (CANEO *et al.,* 2012)(MILLER *et al.,* 2011) (SHILLINGFORD *et al.,* 2008). According to the Brazilian Society of Cardiovascular Surgery (BSCVS), only 30% of the children diagnosed with congenital heart disease are able to undergo surgical intervention, and the situation is worse in the North and Northeast regions. This problem is explained by the rupture of several elements, such as competent professionals, hospitals with available beds, and the construction of more reference centers in pediatric cardiology in the country (ARAGÃO *et al.,* 2013). Although public health policies emphasize the importance of care for children (ALMEIDA; MARGONI; SANTOS, 2016), in cases of congenital heart disease, there is a long way to be travelled since the screening of children with correct diagnosis until clinical or surgical interventions due to the absence of professionals specialized in the area of cardiopediatrics (CONGÊNITAS, 2013). The need

to identify the profile of children submitted to cardiac surgical correction is paramount because the results are important information to subsidize and guide the planning of the assistance to this population, collaborating for the construction and implementation of protocols in multiprofessional health, reducing possible risks for children, and favoring the possibility of increasingly early diagnoses. The objective of this study was to evaluate the profile of children with congenital heart disease who underwent surgical correction at a state pediatric reference hospital in cardiology.

MATERIALS AND METHODS

A retrospective, cross-sectional study with a quantitative and documentary approach was developed at the Intensive Care Unit (ICU) of a pediatric reference hospital in Paraíba, Brazil, which performs high-complexity follow-up and surgery of children and adolescents with diagnosis of congenital or acquired heart disease. The initial sample consisted of 131 children diagnosed with congenital heart disease who underwent cardiac surgery during the period from November 2014 to November 2016. After applying the inclusion and exclusion criteria, we obtained the study population of 101 children. The inclusion criteria were all children diagnosed with congenital heart disease admitted to the ICU in the postoperative period of cardiac surgery. Thirty patients were excluded due to lack of information in the medical records and because they had undergone minor non-corrective procedures. The outcome transference after surgical intervention was used as exclusion criterion in the analyses that involved death and non-death of the patients, since it was not possible to have the actual confirmation of the clinical outcome of the children, because they had been sent to another health service. Thus, 6 children were excluded in the specific analyses, totaling the crossing of 95 children. A semi-structured form was used to collect data fromnotes in the children's medical records. Data were tabulated and analyzed in the Statistical Package for Social Sciences (SPSS, Inc., Chicago, U.S.A), version 20.0. The level of significance was set at $p < 0.05$ (5%). Descriptive and inference analyses were presented in tables. The Chi-square test and the Fisher's exact test were chosen to investigate the associations of dependence between categorical variables. The study was developed taking into account ethical precepts, through the Brazil Platform, in accordance with the requirements of the National Commission for Research Ethics (CONEP) and the National Health Council, and was approved by the Research Ethics Committee under CAAE: 63995416.7 .0000.5177.

RESULTS

One hundred and one records of children and adolescents diagnosed with congenital heart disease were analyzed. Socio-demographic data, place from where the patient came, and surgical outcomes of the children are presented in Table 1. The sample consisted mostly of female patients, totaling 55.4%. As for the age group, the majority (40.6%) were infants (29 days to less than 2 years old). The residence was the main place from where the patient came (74.3%) before the surgical interventions. Regarding outcomes after surgical procedures, it was found that 81.2% of the children and adolescents were discharged and returned to their homes. For this study the classification of congenital heart diseases adopted was based on the presence or absence of cyanosis (cyanotic and

acyanotic), taking into account the diagnoses reported in the medical records. In the sample, 83.3% of the children had acyanotic heart defects, and among them, Interventricular Communication (IVC) (24.8%) followed by Persistence of the Arterial Channel (PAC) (23.8%) prevailed. In order to correct cardiopathies, definitive surgeries (87.1%) with use of Extracorporeal Circulation (ECC) were used in 60.4% of these surgical procedures, as shown in Table 2.

Table 1. Socio-demographic data and outcomes of children, Brazil, 2018

Variables	N	%
Sex		
Female	56	55.4
Male	45	44.6
Age group		
0 |-- 28 days	08	7.9
29 days|-- 2 years	41	40.6
2 |-- 6 years	22	21.8
6 |-- 10 years	25	24.8
10|-- 13 years	05	5.0
Coming from		
Home	75	74.3
Health establishment	23	22.8
Not informed	03	2.9
Outcome		
Discharge	82	81.2
Death	13	12.9
Transference	06	6.0
Total	101	100
Source:Direct search, 2017		

Table 2. Distribution of congenital heart diseases according to clinical variables, Brazil, 2018

Variables	N	%
Types of cardiopathies		
Acyanotic		
IVC	25	24.8
PAC	24	23.8
VASD	16	15.8
IAC	10	9.9
CoAo	5	5.0
RV Hypoplasia	3	3.0
Valvopathies	1	1.0
Total	84	83.3
Cyanotic		
T4F	13	12.9
TAPVD	3	3.0
TGA	1	1.0
Total	17	16.9
Types of surgery		
Definitive	88	87.1
Palliative	13	12.9
Total	101	100
ECC		
Yes	61	60.4
No	40	39.6
Total	101	100

Source: Direct search, 2017 LEGEND: IAC- Interatrial Communication, IVC-Interventricular Communication, CoA- Coarctation of the Aorta, PAC-Persistence of the Arterial Channel, VASD- Ventricular Atrial Septal Defect, RV Hypoplasia- Right Ventricle Hypoplasia, T4F- Tetralogy of Fallot, TAPVD - Total Anomalous Pulmonary Venous Drainage, TGA- Transposition of the Great Arteries, ECC- Extracorporeal Circulation

In order to analyze the association between death and clinical variables, cases that were transferred and whose destination was not informed (6 cases) were excluded from the sample, and only cases of discharge and death were kept, totaling 95 cases. The table below shows the association of death with the following clinical variables: type of surgery; major invasive devices used in the cardiac surgery such as mean arterial pressure (MAP), central venous access (CVA), drain,

cardiopulmonary bypass (CPB); trans- and post-operative intercurrences; and types of cardiopathies according to presence or absence of cyanosis. A significant association between type of cardiopathy and type of surgery with death was observed, with greater frequency in cyanotic heart diseases (38.5%) and palliative procedures (33.3%). However, there was no significant difference in those who used MAP, CVA, CPB, and patient outcome (p> 0.05). Patients who did not present intraoperative complications and those who used mediastinal drain had a better outcome than those who used chest drain or both drains; however, although a large part of the patients presented complications in the post-surgical period, they were able to progress satisfactorily to discharge (Table 3). As for the cardiopathy groups and the presence of death, it was verified that cyanotic cardiopathy was significantly associated with death (p = 0.03).

Table 3. Association of death (n = 95) with clinical and surgical variables and presence of trans- and post-surgical complications, Brazil, 2018

Variables	DEATH		
	Yes n (%)	No n (%)	*p
Surgery			
Definitive	9(10.8)	74(89.2)	0.034*
Palliative	4(33.3)	8(66.7)	
MAP			
Yes	13(14.3)	78(85.7)	0.416*
No	0(0.0)	4(100.0)	
CVA			
Yes	13(14.7)	78(85.7)	0.416*
No	0(0.0)	4(100.0)	
Drain			
MD	9(15.0)	51(85.0)	
CD	3(8.8)	31(91.2)	0.029*
Both	1(100.0)	0(0.0)	
ECC			
Yes	9(15.5)	49(84.5)	0.515*
No	4(10.8)	33(89.2)	
Trans-operative intercurrences			
Yes	5(24.9)	12(70.6)	0.037*
No	8(10.3)	70(89.7)	
Post-operative intercurrences			
Yes	13(26.3)	42(76.4)	0.001**
No	0(0.0)	40(100.0)	
Cardiopathy			
Acyanotic	8(12.2)	72(87.8)	0.030**
Cyanotic	5(38.5)	10(61.5)	

Source: Direct search, 2017 **LEGEND:** CVA- Central Venous Access, MD-Mediastinal Drain, CD- Chest Drain, ECC - Extracorporeal Circulation, MAP-Mean Arterial Pressure. * Chi-square test; ** Fisher's exact test

Table 4. Association of cardiopathies with the occurrence of death, Brazil, 2018

Variables	Total	Death		
	N (%)	Yes n (%)	No n (%)	*p
Types of cardiopathies				
IVC	25 (26.3)	1(4.0)	24(96.0)	0.101*
PAC	22 (23.2)	2(9.1)	20(90.9)	0.475*
VASD	15 (15.8)	2(13.3)	13(86.7)	0.966*
T4F	11 (11.6)	3(27.3)	8(72.7)	0.163*
IAC	10 (10.5)	0(0.0)	10(100.0)	0.183*
CoA	4 (4.2)	0(0.0)	4(100.0)	0.416*
TAPVD	3 (3.2)	1(33.3)	2(66.7)	0.314*
RV Hypoplasia	3 (3.2)	3(100.0)	0(0.0)	0.002**
TGA	1 (1.1)	1(100.0)	0(0.0)	0.012*
Valvopathies	1 (1.1)	0(0.0)	1(100.0)	0.689*
Total	95(100.0)	13(13.7)	82(86.3)	

Source: Direct search, 2017 **LEGEND:** IAC- Interatrial Communication, IVC- Interventricular Communication, CoA- Coarctation of the Aorta, PAC-Persistence of the Arterial Channel, VASD- Ventricular Atrial Septal Defect, RV Hypoplasia- Right Ventricle Hypoplasia, T4F- Tetralogy of Fallot, TAPVD - Total Anomalous Pulmonary Venous Drainage, TGA- Transposition of the Great Arteries. * Chi-square test; ** Fisher's exact test

Table 4 also shows the association between the types of cardiopathies and the occurrence of death in the postoperative period. It was seen that death was statistically associated with right ventricle hypoplasia and Transposition of the Great Arteries (TGA). When the type of heart disease was related to the age at which the surgical procedure was performed, acyanotic heart disease of the CIV type (26.3%) was the most frequent in children and adolescents older than 12 months, with a significant difference (p = 0.026).

DISCUSSION

In the present study, it was observed that congenital heart diseases were more frequent in females and in the age range of infants (29 days to less than 2 years old), a fact also observed in the research by Belo et al.(2016), which aimed to trace the clinical-hospital profile of 77 children diagnosed with congenital heart disease in a pediatric ICU of a reference hospital in the state of Paraná. In their study, the age was extended up to 2 years and 3 months. Similar findings were also reported by Aragão *et al.* (2013) in their research carried out in the Northeast of Brazil, specifically in the city of Aracajú, from 2005 to 2010, totaling 300 patients with congenital heart disease. It is noteworthy that it is this time that children and adolescents usually take between finding out the diagnosis and the surgical correction, although some diagnoses of heart diseases are detected since the intrauterine period, accelerating the management of adequate care. Early surgical procedures are preferred for correction of physiological changes coming from congenital heart diseases, since they lead to better indices of quality of life and survival in these children (BELO *et al.,* 2016). Regarding the place where the children came, it was seen that most of them had come from their homes to the health service (CPAM) to perform the surgical correction, with a whole health network already organized and schematized to receive these children. The PEPB RCP support contributes to reduce the waiting time between the disclosure of the diagnosis and the arrival to the specialized cardiology department in case of pathologies that needed surgical corrections. In this same perspective (SILVA, 2015), in a cross-mapping, with nursing diagnoses in children with heart disease, it was observed that 75.6% came from their homes for hospital admission. It can be inferred that, if they came from their homes, the children and adolescents presented adequate health status, with less risk of complications and better prognosis after surgical interventions. This corroborates with the results of Cappellesso and Aguiar (2017) who demonstrated a high percentage of children who returned to their homes after cardiac surgeries, evidencing hospital discharge as the main clinical outcome after the period of hospitalization in a children's hospital. However, a high number of deaths were observed in this study, confirming the association of heart diseases with infant mortality. In the present study, the rate of children and adolescents who were able to return home prevailed; however, it is noteworthy that some users did not have their final destination analyzed because of transfer to other health services, and they may have suffered interference from this transference and have changed the course of this return to home. Despite the satisfactory result observed in the research, attention is drawn to the mortality that still occurs after surgical procedures, or even during them. There is a need for revision of protocols and development of instructive materials for public services in order to favor the treatment of these children, as well as to warn of the need to develop an effective public health policy

that contemplates this public, although the figures do not represent the totality of children and adolescents diagnosed with congenital heart diseases. Worldwide, CC are responsible for up to 30% of deaths and the most worrying is that up to 70% of serious cardiac patients do not reach adult age. CC has a high mortality rate in children under one year of age, reaching up to 3% in neonates. In a developed country such as the United States, about 40,000 newborns have heart defects, and these CCs are responsible for more than 40% of deaths in children under one year of age. In Latinos, they are the second cause of death in this population, thus constituting a public health problem (CAPPELLESSO; AGUIAR, 2017) (AHA, 2017). According to the same authors (CAPPELLESSO; AGUIAR, 2017) (AHA, 2017), although there are already public policies in Brazil focused on this area and on the improvement of the quality of diagnostic methods and treatments, they do not work properly, and the prognosis depend on several factors related to the severity of the heart disease, interfering with the correct growth and development that may influence the quality of life of the cardiac patient. Surveys affirm the importance of carrying out surgical repairs up to twelve months of age, but the large portion of the population that needs such care is not able to reach health services in a timely manner.

These data are more alarming when studying the North and Northeast regions of the country. Regarding the types of cardiopathies, the acyanotic ones prevailed and among these, the IVC was the most incident. Among the cyanotic cardiopathies, T4F stood out. Such findings are similar to the important research of Aragão *et al.* (2013), who analyzed the epidemiological profile of 300 patients with congenital heart disease, where about 70% of the heart diseases were acyanotic, with prevalence of interventricular septal defects, followed by PCA, and among the acyanotic diseases, T4F stood out with a percentage near to 14%. This higher rate of simpler cardiopathies may have occurred due to the implantation of the pulse oximetry test in maternity wards in Paraíba. They alert for suggestive or suspected cases of congenital cardiopathies, and allow a greater efficiency in the early diagnosis by the CPR PE -PB and the practice of effective interventions in simple or severe injuries. Coupled with the pulse oximetry test, we must pay attention to other steps of the care in the early detection of cardiac congenital abnormalities. To that end, Fillipps and Bucciarelli (2015) affirm that the detailed physical examination in all phases is essential in the care of neonates soon after delivery or before discharge. In the presence of complex congenital heart diseases, anomalies in the heart and vessels of great caliber lead to a decrease in the amount of oxygen reaching the peripheral regions due to the combination of blood from the systemic and pulmonary circulations. The measurement of saturation in neonates through pulse oximetry has been established as an important resource in the early identification of cardiovascular alterations (BORGES, 2013) (SCHROEDER *et al.*, 2014). After detection of any congenital cardiac anomaly and chronicity, treatments may be clinical with medication administration, may include monitoring, or even dependent on surgical corrections. As presented in the research all users were submitted to surgical procedures, with predominantly definitive approach with the objective of restoring the adequate standard of living. Surgeries may be of the palliative type, which organize the patients for future definitive procedures, or they may even be characterized as permanent due to the clinical picture of morphological incoherence or function, making it impossible to advance to a definitive surgical correction. The definitive approach, in turn, is capable of remodel the anatomical or functional structures of the cardiac organ (SOUZA; ANDREOLI, 2017). Surgical interventions can still be divided between those which use ECC or not. With the evolution of mechanical circulatory assistance, heart diseases that were previously impossible to be surgically addressed because ofincreased morbidity and mortality, began to have an alternative, contributing to a better prognosis. ECC is used as a tool during surgery and although it is being constantly improved, it is present in 90% of surgeries in the intraoperative phase[19]. These data is in line with the percentage of children and adolescents who used ECC in the cardiac surgeries of the present study, as shown in the research. After cardiac surgery, with the use of ECC in most cases, the patients are taken to the Pediatric Cardiac Intensive Care Unit (UTICP), under invasive mechanical ventilation through orotracheal tube, often including invasive devices such as PAM, mediastinal or chest drain, central venous access, often dependent on vasoactive drugs, to maintain hemodynamic homeostasis (SILVA *et al.,* 2017). Although ECC is an already well-established procedure with constantly evolving technology, it can lead to changes in already known human physiology, or may cause adverse effects yet unknown. Such complications may be related to the long-term use of this procedure and may depend on the type of disease, sex, and extremes of age, especially in neonates, due to the immaturity of the body. The main types of complications that ECC may entail are those related to pH, glycemia, among others (OLIVEIRA *et al.,* 2015).

The research showed that despite the fact that most of the children presented trans- and post-operative complications, they achieved a good clinical outcome, with evolution to discharge and return to home, which calls attention to the valorization of adequate management of individualized care to patients, and for this kind of attention it is necessary that the UTICP health team have thorough knowledge of all the information of the trans-operative procedure. As the study was based on secondary data, it is suggested to review these data, as well as a better completion of forms and records of nursing care. They must include correct and reliable notes in the medical records of clinical and water balance, checking the amount of blood and urine eliminated, correct use of the quantity, timing, and administration of drugs, and the need for effective communication among all professionals providing care. ICU Patients, especially after cardiac surgical procedures, are constantly monitored by devices. However, surveillance and health care in the entire hospitalization process, at the bedside, should be emphasized and performed by the whole health staff. As the nursing team is usually the one that spends most time with patients, it is important to train these professionals, using institutional routines and protocols for the comprehensive care of critically ill children and adolescents such as those who undergo invasive cardiac procedures so as to reduce the risk of complications or even death. To collaborate with the previously described thinking, a prospective cross-sectional study using scales to assess the complexity of nursing care in children undergoing cardiac surgery was adopted to affirm the adequate number for a satisfactory work of the nursing staff in the complex care for children who underwent cardiac surgery. Adequate analysis of the variety of care measures favors an appropriate dimensioning of the nursing staff to ensure effective care. The recognition of changes presented by the patients is of fundamental importance in the work of the nursing team.

Identifying the changes and their proportion makes it possible to divide the tasks among professionals, contributing to the quality of the care provided and the adequate clinical evolution of patients (HOSCHEIDT *et al.,* 2014). It should be noted that the procedures were mostly carried out in children older than 12 months, but the literature recommends that many heart diseases should be treated before this age, even because many can be identified since the intrauterine stage. The knowledge of CC in prenatal care also allows health professionals and institutions to prepare for the birth of this child, reducing the chances of morbidity and mortality (CORREIA *et al.,* 2015). Because of the congenital nature, timely diagnosis and treatment are essential to avoid future problems, favoring an improvement in the quality of life of these children (BARROS *et al.,* 2014). The results of the research pointed that mortality is more related to more complex heart diseases such as right ventricle hypoplasia and TGA in children under 12 months and using ECC. Therefore, it is important to emphasize that the timely recognition of the type of CC and early therapy of congenital deformities are the consequence of the influence of several factors, among them the important work of a multidisciplinary team, with respect to the different health classes horizontally, as well as the commitment of those involved in the process, because the final product has a direct relation with the commitment of each specialist member (FROTA *et al.,* 2014).

Conclusion

A clinical and epidemiological profile with higher frequency of female infants from Paraíba Atlantic rainforest, coming from their homes, was observed in this study. The main outcome was the return to home, after corrective surgeries. There was a predominance of acyanotic congenital cardiopathies, of the IVC type, and among cyanotic cardiopathies there was a prevalence of T4F; however, the most common heart diseases were RV Hypoplasia and TGA. It was observed that, although the proportion of deaths was low, occurring in 13 children out of a total of 101, there was an association with the type of surgery, type of heart disease, use of invasive devices such as a drain, and those who evolved with intercurrences that occurred in trans- or post-surgical periods. With the survey examined in the research showed that few studies have evaluated the profile of congenital heart diseases, especially in the nursing area, to improve the actions in the work process. This indicates a need to review and create care routines and protocols for children with this type of disease that are submitted to surgical correction. This approach may help to reduce morbidity and mortality, prevent complications, and further reduce deaths. In this sense, it is suggested that more studies are carried out in this area, contemplating pathologies associated with congenital heart diseases that can lead to other types of complications. It is hoped to collaborate on the theme and to assist the health professionals, providing greater knowledge regarding the nursing care in the approach of congenital heart diseases.

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