ORIGINAL ARTICLE

Waiting for Cardiac Procedure in Congenital Heart Disease: Portrait of an a Hospital in the Amazonian Region

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Abstract

Background: Congenital heart disease is an important cause of morbidity and mortality in childhood, and in 50% of cases, surgery is required in the first year of life. A high deficit of surgical procedures is estimated in Northern Brazil.

Objective: To analyze the waiting time for elective surgical treatment and/ or intervention in children with congenital heart disease in a Cardiology referral center, and to make considerations about heart diseases and forms of treatment in that institution.

Methods: A cross-sectional study of all patients aged less than 14 years, with a diagnosis of congenital heart disease that were waiting for elective surgical or percutaneous cardiac treatment.

Results: Among the 407 children with congenital heart defects, the most prevalent age group was > 2 to 6 years (34.0%). The average waiting time was 23.1 ± 18.3 months, with a median of 19. The most frequent heart disease was ventricular septal defect (28.98%), patent ductus arteriosus (18.42%) and atrial septal defect (11.05%). Most children (63.4%) were not from the metropolitan area. The percutaneous interventions represented only 27.84% of the catheterization procedures and 14,85% of all heart treatments. Approximately 60% of the pediatric surgeries occurred in children who were not previously registered due to urgency cases.

Conclusion: Most of the children waiting for a cardiac procedure were not from the metropolitan area and had malformations potentially treatable by catheterization. It is necessary to increase the capacity of the single referral center in the state of Pará, as well as decentralize the high-complexity cardiological care in the metropolitan region. (Int J Cardiovasc Sci. 2018;31(4)374-382)

Keywords: Heart Defects, Congenital / therapy; Waiting Lists; Heart Defects, Congenital / surgery; Epidemiology.

Introduction

Congenital heart defects, defined as structural abnormalities of the heart or the intrathoracic vessels, in different anatomical forms, are one of the most frequent congenital anomalies identified at birth.[1-3] These malformations are the ones with the greatest impact on children's morbidity and mortality and on the cost of health services[4] and they represent the main cause of death among all congenital malformations.[5]

The prevalence of congenital heart diseases is between four and nine per thousand live births, with an estimated 1.5 million new cases per year worldwide.[2,6,7]

Hoffman estimated that between 1940 and 2002, 1.5 million people were born in the United States affected by heart disease.[2] In Brazil, 28,846 new cases of congenital heart disease are estimated per year. Spontaneous cure occurs in approximately 20% of the cases, related to less complex defects with a mild hemodynamic effect.[8]

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The estimated need for surgical procedures to repair congenital heart defects is 7.2 per thousand births, with reports of more significant deficits for treatment in the North and Northeast Regions, with rates close to 90%, and less significant in the Southern and Midwest regions, with rates of 46.4% and 57.4%, respectively.[8,9]

Congenital heart diseases are important causes of hospital admissions in the pediatric population, and the earlier the diagnosis and the therapeutic intervention of these conditions, the lower the mortality and hospital readmission rates, and the better the quality of life of these children.[10]

Considering the severe or potentially severe nature of these cardiopathies, which may have significant effects for morbidity and mortality, it is essential to know the reality of heart diseases in the only public referral hospital for these conditions in the State of Pará, Brazil.

The aim of this study was to analyze the waiting time for elective surgical and/or interventional treatment in children with congenital heart defects in a cardiology referral center, as well as to evaluate the patients' origin and make considerations about heart diseases and their types of treatment in that institution.

Methods

Cross-sectional study of patients aged 14 years or less, diagnosed with congenital cardiac malformations, who were waiting for surgical or percutaneous cardiac treatments, including reoperation cases.

The data were obtained from the medical and statistical archive service (SAME) of *Fundação Hospital de Clínicas Gaspar Vianna*. The study variables were: gender, age, place of residence, diagnosis and time waiting for the procedure. Additionally, data from patients submitted to surgical and/or catheterization treatment were collected from January 2012 to October 2014.

The descriptive analysis of data was performed using the BioStat program, and the variables were shown as measures of central tendency and dispersion or frequencies.

The present study was submitted to and approved by the Research Ethics Committee Involving Human Beings of Fundação Hospital de Clínicas Gaspar Vianna, under CAAE number 39903014.2.0000.0016.

Results

Of the 417 children waiting for cardiac surgery or hemodynamic procedure, 407 had a diagnosis of congenital heart disease; of these, 55.1% were females, and the most prevalent age groups were preschoolers (> 2 to 6 years), with 34.0%, and schoolchildren (> 6 to 12 years), with 33.3% (Table 1). The mean age was 5.7 (± 3.9), with a median of 5.0 years, ranging from 1 month to 14 years. There were no neonates waiting for treatment.

The mean waiting time, in months, was 23.1 ± 18.3, with a median of 19, a minimum of 1 month and a maximum of 94 months. The two patients who had been waiting for 91 and 94 months (longer waiting periods) were incommunicable by the social service of the institution, which may justify the delay.

Regarding their origin, 36.6% came from the municipality of Belém Metropolitan Mesoregion, followed by 27.2% from the Northeast of Pará, 17.6% from the Southeast of Pará and the remaining 18.1% from the Lower Amazon region, Southwest of Pará and Marajó together; one patient was from Amapá state (Figure 1).

The most commonly diagnosed type of congenital heart disease was ventricular septal defect (VSD), isolated or associated with other cardiac malformations, totaling 28.98%, followed by persistent ductus arteriosus (PDA) with 18.42%, atrial septal defect (ASD) with 11.05%, with or without associations, and Tetralogy of Fallot, with 8.59% (Table 2).

Regarding the performed surgeries, in 2012, 172 children underwent 201 pediatric cardiac surgeries; in 2013, 176 patients underwent 207 surgeries; and in 2014, until October 146 children underwent 158 cardiac surgeries. In 85.3% of the cases, it was possible to determine whether the child was previously enrolled for elective treatment or not: in 2012, 62.2% were not enrolled, being submitted to emergency procedures, and only 37.7% belonged to the elective enrollment group. In 2013, the same thing occurred, with 59.0% and 40.9% of cases, respectively (Table 3).

In 2012, an average of 16.7 pediatric heart surgeries were performed per month. In 2013, this average was 17.2 and in 2014, until the end of October, of 15.8. Among pediatric hemodynamic procedures, there was a greater increase: in 2012, the average number of monthly procedures was 9.5, in 2013, 9.8 and until October 2014, 13.6 (Table 4).

Regarding the type of hemodynamic procedure, the rate of cardiac diagnostic catheterization was 73.9%, while the rate of therapeutic interventions corresponded to 26.1% of the total procedures performed since 2012 (Table 5, Figure 2).

Table 1 - Patients enrolled for elective pediatric cardiac procedures

Characteristic	n total (%)
Gender	
Male	183 (44.94)
Female	224 (55.06)
Age group, years	
< 1	45 (11.06)
1-2	66 (16.22)
> 2-6	142 (34.89)
> 6-12	133 (32.68)
> 12	21 (5.16)
Waiting time	
< 1 month	0
1-6 months	80 (19.66)
7 months-1 year	50 (12.29)
> 1-3 years	197 (48.4)
> 3-5 years	57 (14)
> 5 years	23 (5.65)
Pará Mesoregion*	
Belém Metropolitan Area: Ananindeua, Barcarena, Castanhal, Santa Izabel do Pará, Belém, Santo Antonio do Tauá, Benevides and Marituba	149 (36.60)
Northeast of Pará: Abaetetuba, Santa Luzia do Pará, Acará, Irituia, Santa Maria do Pará, Augusto Corrêa, Aurora do Pará, Mãe do Rio, São Caetano de Odivelas, Baião, São Domingos do Capim, Maracanã, Bragança, Marapanim, Mocajuba, São João de Pirabas, Cametá, Moju, São Miguel do Guamá, Capanema, Nova Esperança do Piriá, Tailândia, Capitão Poço, Colares, Oeiras do Pará, Tomé-Açu, Ourém, Tracuateua, Curuçá, Peixe-Boi, Primavera, Viseu, Igarapé-Açu, Igarapé-Miri and Salinópolis	111 (27.27)
Southeast of Pará: Rio Maria, Itupiranga, Rondon do Pará, Jacundá, Bom Jesus do Tocantins, Marabá, Santana do Araguaia, Nova Ipixuna, Breu Branco, Novo Repartimento, São Félix do Xingu, Canaã dos Carajás, Conceição do Araguaia, Paragominas, Curionópolis, Parauapebas, Tucumã, Dom Eliseu, Pau D'arco, Tucuruí, Eldorado do Carajás, Ulianópolis, Redenção and Xinguara	72 (17.69)
Lower Amazon: Alenquer, Juruti, Almeirim, Monte Alegre, Prainha, Óbidos, Santarém, Curuá, Oriximiná and Placas	33 (8.10)
Marajó: Curralinho, Salvaterra, Anajás, Gurupá, Melgaço Breves, Soure, Cachoeira do Arari, Ponta de Pedras, Chaves and Portel	22 (5.40)
Southwest of Pará: Altamira, Medicilândia, Pacajá, Itaituba and Rurópolis	19 (4.66)

** For all characteristics, n = 407, for mesoregions, n = 406; † except for one patient from Santana (AP).*

Of the total of 662 therapeutic cardiac procedures performed between 2012 and October 2014, 86.1% corresponded to cardiac surgeries and only 13.8% to percutaneous interventions. This proportion remained stable over the years (Table 6).

Discussion

In Brazil, it is estimated that the average need for cardiovascular surgery in congenital cases is approximately 23,000 procedures/year, considering in

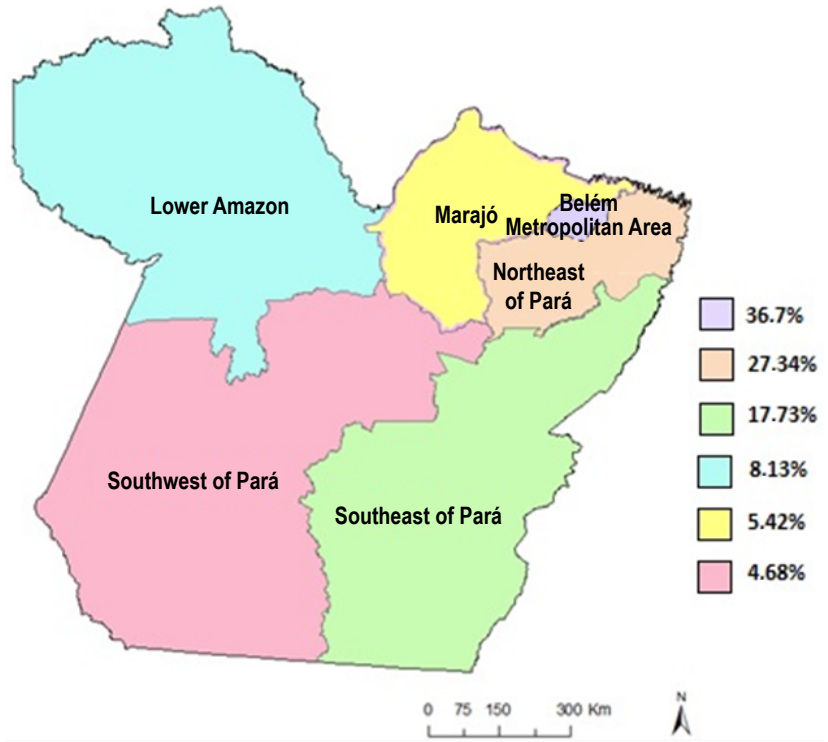

Figure 1 - Distribution of patients waiting for elective pediatric cardiac procedures according to the place of residence in mesoregions.

this estimate, in addition to new births with congenital heart disease, the reintervention cases. In 2002, a total of 8,092 patients underwent surgery, which shows a 65% gap – with higher rates in the Northern Region (93.5%).[9]

In the present study, it was observed that of the 407 children diagnosed with congenital heart disease, the most prevalent age groups were preschoolers (> 2 to 6 years) and schoolchildren (> 6 to 12 years), with no neonates waiting for treatment. These results differ from those observed in the analysis of the prevalence of congenital heart diseases at the time of the first consultation in a pediatric hospital in the city of Curitiba, state of Paraná, where there was a predominance of children with congenital heart disease in the infancy period, followed by the neonatal period, with 52.1%, and 19.4%, respectively.[11] Considering that the sample of the present study refers to the patients waiting for elective procedures, this may reflect the differences regarding the time of referral for these patients and the delay during the waiting period.

Regarding the type of congenital heart disease, the most frequent one was VSD, followed by PDA and ASD. These results are consistent with those found in the study by Aragão et al.,[12] who demonstrated the following frequencies: VSD (21%), PDA (18%), Tetralogy of Fallot (14%) and ASD (7.7%). As for Huber et al.,[13] they were as follows: VSD with or without associations (13.9%), Tetralogy of Fallot (12.9%), obstructive lesions of the right ventricular outflow tract (9.8%), and isolated ASD (9.6%). It can be said that the assessed institution had similar characteristics to those observed in other regions of Brazil.

The most frequent origin of the children who comprised the waiting list for cardiologic procedures was the Belém Metropolitan Mesoregion, a result consistent with those of a referral hospital in the Northeast region of Brazil, where most of the children came from the metropolitan region of the state.[12]

However, 63.4% of the children did not live in the Metropolitan Region of Belém; thus, a point to be discussed is the need to qualify new high cardiovascular complexity referral units in the State of Pará. For the geographical distribution of the High Complexity Care Services in Pediatric Cardiovascular Surgery, according to Ordinance 210,[14] which is based on the proportion of 1:800 thousand inhabitants, the State of Pará needs nine centers capable of performing pediatric cardiovascular surgery, but the regionalization of services has not yet occurred, generating

Table 2 - Type of congenital heart disease of patients enrolled for elective procedure

Cardiopathies	n (%)
Ventricular septal defect	110 (27.02)
Patent ductus arteriosus	75 (18.42)
Atrial septal defect	41 (10.07)
Tetralogy of Fallot	35 (8.59)
Congenital pulmonary stenosis	24 (5.89)
Coarctation of the aorta	15 (3.68)
Pulmonary atresia	12 (2.94)
Ventricular septal defect + associations*	8 (1.96)
Congenital aortic stenosis	8 (1.96)
Atrioventricular defect	7 (1.71)
Double-outlet right ventricle	5 (1.22)
Congenital tricuspid stenosis	5 (1.22)
Congenital mitral regurgitation	5 (1.22)
Hypoplastic right heart syndrome	4 (0.98)
Common arterial trunk	3 (0.73)
Double inlet left ventricle	3 (0.73)
Atrial septal defects + pulmonary stenosis	3 (0.73)
Congenital subaortic stenosis	2 (0.49
Cor triatriatum	1 (0.24)
Ebstein's anomaly	1 (0.24)
Hypoplastic left heart syndrome	1 (0.24)
Anomalous pulmonary venous return	1 (0.24)
Cardiac aneurysm	1 (0.24)
Discordant atrioventricular connection	1 (0.24)
Discordant ventriculoatrial connection	1 (0.24)
Double outlet left ventricle	1 (0.24)
Aortic regurgitation	1 (0.24)
Double mitral valve lesion	1 (0.24)
Congenital pulmonary insufficiency	1 (0.24)
Others†	34 (8.35)

** Patent ductus arteriosus, atrial septal defect, pulmonary stenosis and coarctation of the aorta; † other congenital malformations of the tricuspid valve, other congenital malformations of the cardiac chambers and connections, congenital malformations of the cardiac septa, non-specific congenital malformation of the tricuspid valve, malformations of the coronary vessels, primary and secondary pulmonary hypertension, and unregistered ones.*

a deficit of 78.49%.[15] This reality can be explained by several causes, such as the lack of qualified professionals and hospital institutions with infrastructure to perform the required complex procedures.

In our reality, there is also the hypothesis that the low rate of patients coming from the Lower Amazon region, Marajó island and southwest of Pará regions is due to the difficulties of access to basic care for this population, thus resulting in the underdiagnosis of congenital heart diseases and, therefore, fewer referrals to the assessed center.

A highly complex service requires multiprofessional attention, with cardiac surgeons, hemodynamicists, pediatric cardiologists, anesthesiologists, pediatric intensivists, in-hospital and outpatient clinic pediatricians, perfusionists, nurses and physical therapists. The treatment outcomes should be part of a lifelong care cycle, and not only the immediate surgical outcome. The large number of patients with cardiac malformations requires multi-institutional cooperation to achieve these goals.[16]

Fundação Hospital de Clínicas Gaspar Vianna is the only referral public hospital in Pará that performs hemodynamic and surgical treatment of pediatric congenital heart disease. The mean monthly number of cardiac surgeries was similar in the study period (16.6 surgeries/month). Regarding pediatric hemodynamic procedures (diagnostic and/or therapeutic cardiac catheterization), there was an increase: in 2012, the average number of monthly procedures was 9.5; in 2013, of 9.8; and in 2014, until October, of 13.6 – it is noteworthy that this increase was accompanied by an increase in the number of diagnostic cardiac catheterizations to the detriment of therapeutic ones. The latter, in turn, accounted for only 14.85% of all therapeutic procedures.

The low number of therapeutic cardiac catheterizations when compared to diagnostic procedures is a consequence of the absence of other diagnostic methods, such as computed tomography and cardiac magnetic resonance, due to the possible lack of devices for therapeutic percutaneous procedures.

Considering that VSD, ASD, PDA, congenital pulmonary stenosis and coarctation of the aorta account for 65.2% of all diagnoses, which are malformations potentially treatable by cardiac catheterization, it can be observed that there is a low rate of these interventions in our country. Thus, investing in hemodynamic treatment is a strategy to reduce the waiting time, since the interventional treatment does not require prolonged

Table 3 - Patients submitted to pediatric cardiac surgery according to the enrollment status in the waiting list for cardiac procedures

Month	2012 (n = 201)			2013 (n = 207)		
	Enrolled	Not enrolled	Not informed	Enrolled	Not enrolled	Not informed
January	8 (3.98)	8 (3.98)	1 (0.50)	5 (2.42)	11 (5.31)	6 (2.90)
February	6 (2.99)	5 (2.49)	3 (0.49)	6 (2.90)	14 (6.76)	5 (2.42)
March	4 (1.99)	10 (4.98)	4 (1.99)	8 (3.86)	17 (8.21)	2 (0.97)
April	0	3 (1.49)	2 (1.00)	6 (2.90)	3 (1.45)	2 (0.97)
May	0	12 (5.97)	0	6 (2.90)	4 (1.93)	0
June	4 (1.99)	14 (6.97)	2 (1.00)	4 (1.93)	7 (3.38)	2 (0.97)
July	6 (2.99)	6 (2.99)	3 (1.49)	5 (2.42)	12 (5.80)	6 (2.90)
August	4 (1.99)	12 (5.97)	5 (2.49)	6 (2.90)	11 (5.31)	1 (0.48)
September	9 (4.48)	5 (2.49)	2 (1.00)	6 (2.90)	6 (2.90)	4 (1.93)
October	12 (5.97)	8 (3.98)	1 (0.50)	8 (3.86)	7 (3.38)	0
November	5 (2.49)	13 (6.47)	3 (1.49)	4 (1.93)	8 (3.86)	1 (0.48)
December	7 (3.48)	11 (5.47)	3 (1.49)	8 (3.86)	4 (1.93)	2 (0.97)

Table 4 - Surgical and hemodynamic procedures (diagnostic and therapeutic) performed per year

Month	Surgical procedures			Hemodynamic procedures		
	2012	2013	2014	2012	2013	2014
January	17	22	21	10	9	18
February	14	25	17	8	7	4
March	18	27	16	7	11	11
April	5	11	18	3	3	13
May	12	10	13	13	9	15
June	20	13	15	11	11	14
July	15	23	17	14	14	15
August	21	18	15	12	9	12
September	16	16	12	20	12	20
October	21	15	14	6	18	13
November	21	13	-	4	8	-
December	21	14	-	7	7	-

hospital length of stay,[17] and therefore favors a greater turnover of recovery beds, consisting of pediatric intensive care units and pediatric ward beds.

At the same time, it can be observed that at *Instituto do Coração* of *Hospital das Clínicas* of *Faculdade de Medicina* of *Universidade de São Paulo*, the number of percutaneous

Table 5 - Hemodynamic procedures performed according to the type of intervention per year

Procedure	2012	2013	2014
Diagnostic cardiac catheterization	77	87	108
Diagnostic cardiac catheterization + percutaneous intervention	24	27	27
Cardiac catheterization + angioplasty	23	17	13
Cardiac catheterization + embolization	0	3	0
Cardiac catheterization + PDA/ ASD/ VSD closure	0	3	5
Cardiac catheterization + atrial septostomy	0	1	0
Cardiac catheterization + valvuloplasty	1	3	9
Percutaneous intervention	14	4	0
Pulmonary Embolization	1	1	0
Valvuloplasty	5	1	0
Angioplasty	8	1	0
PDA closure	0	1	0

PDA: patent ductus arteriosus; ASD: atrial septal defect; VSD: ventricular septal defect.

interventions remained stable, with only one record of case that was not treated due to structural limitations, considering the limited number of beds in the institution.[18]

Making investments aiming to reducing the waiting time for congenital cardiovascular procedures also improves morbimortality outcomes. However, this generates high short-term costs to the Brazilian Unified Health System (SUS). The devices used for closure of ASD, VSD and PDA are not covered by SUS, which creates more difficulties in their acquisition. There is also the challenge of financial transfer, sometimes insufficient for cardiac surgeries, limiting their increase. The fact that there is almost no differentiation regarding the payment of the procedure related to its degree of complexity punishes the referral center dedicated to the more complex cases and discourages the increase in the number of procedures in neonates and infants, especially in the higher complexity cases. Some international studies

Table 6 - Cardiac surgery and therapeutic hemodynamic procedures

Treatment	2012	2013	2014
Surgical	201 (84.10)	207 (86.97)	158 (85.40)
Percutaneous	38 (15.89)	31 (13.02)	27 (14.59)

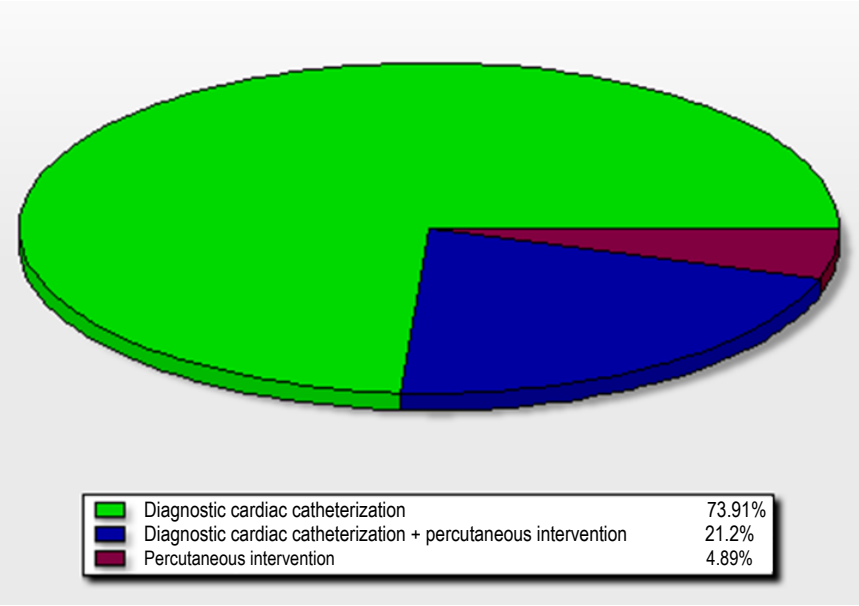

Figure 2 - Type of hemodynamic procedure performed.

have shown that there is a linear association between the complexity and cost of the procedure.[19]

Another great difficulty that the service faces in reducing the waiting list for elective cardiac surgery is the high demand for urgent surgeries in patients without previous enrollment, as these cases are prioritized to the detriment of elective ones. A strategy to mitigate the problem in the short term would be the performance of congenital heart surgeries in patients already enrolled for it, aiming to reduce the repressed demand of SUS users.[19]

In this sense, it is proposed: the creation of outpatient care and specialized centers for the diagnosis and early treatment of the population, reducing underdiagnosing and improving pre- and postoperative clinical follow-up, with a possible reduction of costs for out-of-home treatment and, consequently, less social impact for the affected families; investment in diagnosis performed through computed tomography and cardiac magnetic resonance imaging, which would reduce diagnostic cardiac catheterizations and increase the availability of hospital support for therapeutic procedures; the promotion of hemodynamic procedures, including a funding policy for Orthoses, Devices and Special Materials (*Órteses, Próteses e Materiais Especiais* – OPME) not covered by SUS, due to the proven effectiveness and shorter hospital length of stay, with a consequent decrease in hospital expenses and an increase in the volume of treated cases per unit of time; increased functional capacity at the referral hospital; decentralization of surgical and cardiac hemodynamic care, with the internalization of this type of service in medium-sized municipalities, such as Marabá and Santarém, both in the state of Pará; and reliable, detailed and updated data registry regarding the surgical and hemodynamic procedures, for permanent control and evaluation of the outcomes. The promotion of improvements in the care for children with heart disease is a priority and involves the participation of all – public services, professionals and several sectors of society.

Conclusion

Most of the children awaiting cardiac procedures come from outside the metropolitan area and have malformations potentially treatable through cardiac catheterization. However, even with changes in the treatment profile, with the increase in percutaneous procedures in the last years, it still requires further increase.

The limitations of the public hospital system in meeting the great demand of the region for elective therapeutic cardiovascular procedures generate an important care deficit, with the need to increase the functional capacity of the only public referral center for these diseases in the region, as well as decentralization of cardiological, clinical, surgical and hemodynamic care, to better treat the population that depends on SUS.

Author contributions

Conception and design of the research: Jesus VS, Nascimento AM, Miranda RA, Veríssimo AOL. Acquisition of data: Jesus VS, Nascimento AM, Lima JS. Analysis and interpretation of the data: Jesus VS, Nascimento AM, Veríssimo AOL. Statistical analysis: Jesus VS, Nascimento AM. Writing of the manuscript: Jesus VS, Nascimento AM, Lima JS, Tyll MAG. Critical revision of the manuscript for intellectual content: Miranda RA, Tyll MAG, Veríssimo AOL.

Potential Conflict of Interest

No potential conflict of interest relevant to this article was reported.

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Study Association

This study is not associated with any thesis or dissertation work.

Ethics approval and consent to participate

This study was approved by the Ethics Committee of the *Fundação Pública Estadual Hospital das Clínicas Gaspar Vianna* under the protocol number 39903014.2.0000.0016. All the procedures in this study were in accordance with the 1975 Helsinki Declaration, updated in 2013. Informed consent was obtained from all participants included in the study.

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