Congenital Heart Disease in Adults: Outpatient Clinic Profile at the *Hospital das Clínicas* of Ribeirão Preto

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Abstract

Background: Service experiences for adults with congenital heart disease have not been reported in our country.

Objective: To describe the basic clinical profile of adults with congenital heart disease in an outpatient tertiary care center.

Methods: We compiled data on age, gender, place of residence, primary diagnosis, and secondary diagnoses of 413 patients treated for seven years.

Results: G1 (untreated): 195 patients, 51% women, 57% between 14 and 30 years, 80% living in the region. The most frequent heart diseases were ventricular septal defect (VSD) (31%), atrial septal defect (ASD) (29%), and pulmonary stenosis (7%). The predominant secondary diagnoses were hypertension (9%) and arrhythmias (5%). G2 (treated): 218 patients, 56% women, 57% between 14 and 30 years, 81% living in the region. The most frequently treated heart diseases were: ASD (36%), tetralogy of Fallot (14%), coarctation of the aorta (12%), and VSD (11%). Sixty-nine (32%) patients were operated on for congenital heart diseases in adulthood. Sixteen (7%) underwent an interventional catheterization. The predominant secondary diagnoses were hypertension (18%) and arrhythmias (8%).

Conclusion: In the study, most patients were treated invasively, all of them were residents in the region, and most of them were under 40 years of age. Defects such as ASD, VSD, and pulmonary stenosis predominated in the untreated group, whereas in the treated group, most patients had undergone surgical correction of ASD, tetralogy of Fallot, aortic coarctation, and VSD. Hypertension and arrhythmias were relevant in both groups, and a large variety of other comorbidities were also observed. (Arq Bras Cardiol 2010;94(6) : 664-670)

Key words: Heart defects, congenital; outpatients; health profile; tetralogy of Fallot; heart septal defects, ventricular; heart septal defects, atrial; Ribeirão Preto (SP); Brazil.

Introduction

The extraordinary development in the diagnosis and treatment of congenital heart disease which occurred in recent decades allowed the survival of a large number of children who previously had little chance to live, and now require special attention to support their full integration into the community when reaching adulthood. Particularly striking were the advancements in non-invasive diagnosis, cardiac surgery, and interventional catheterization[1]. These resources, available in most states across the country, are the essence of the equally remarkable development of the specialty in our country. The therapeutic success, which allows these patients to reach adulthood, and its systematic follow-up facilitated the emergence of a new population of adults with congenital heart disease. It is estimated that this population, combined with heart defect patients with no treatment indication who naturally reach adulthood, comprised approximately 800 thousand individuals, in 2000, in the United States of America[2]. Considering a 5% annual growth forecast[3], it is likely that this number reached one million individuals by 2005.

The first institution to offer this type of care was located in Toronto, Canada, in 1959, providing continuing assistance to the local traditional pediatric cardiology service. Other centers have emerged gradually in England (1975) and in the United States (1976), responding to the needs of these countries and reflecting innovative institutional initiative capacity[4]. In our country, the systemized care offered to adults with congenital heart disease is restricted to a few centers, in which complete child care has been offered for several decades. Despite its recognized activity, studies on the overall experience of these centers are scarce. Reviewing the articles published in this journal in the last ten years, excluding case reports, as well as patients involved in pediatric studies, we found only four studies dealing specifically with adult congenital heart disease[5-8]. This small but notable experience shows, first, the awakening of a current concern with this type of patient and, second, the need for more discussion of this interesting topic.

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The objective of this study was to evaluate the basic clinical profile of patients treated in the outpatient service for adult congenital heart disease patients, at the *Hospital das Clínicas* of the Medical School of Ribeirão Preto, from January 2nd, 2000 to December 31st, 2007.

Methods

We reviewed the medical records of 413 patients treated during this period, divided into an untreated group (G1) and a group of patients who had undergone a previous invasive therapeutic intervention (surgical or percutaneous) (G2). We collected data on age, gender, place of residence, primary diagnosis, and secondary diagnoses. In patients with more than one lesion, the primary diagnosis was the most hemodynamically important heart disease. Some patients had more than one secondary diagnosis.

Results

Group 1 (N = 195)

Most patients were in the third (n = 60) or second (n = 50) decades of life, with a progressively lower prevalence in subsequent decades. We observed the following: 110 (57%) patients were aged between 14 and 30 (Figure 1), 99 (51%) were women and 96 (49%) were men (Figure 2); 42 (21%) lived in the city of Ribeirão Preto, 115 (59%) in cities of the region, 27 (14%) in Minas Gerais, and 6 (3%) in other states. There was no information on the city or state of residence of five (3%) patients (Figure 3).

Sixty (31%) patients had a ventricular septal defect (VSD); four of them with Eisenmenger syndrome; 56 (29%) had an atrial septal defect (ASD); four of them with significant pulmonary hypertension; and 14 (7%) had mild pulmonary

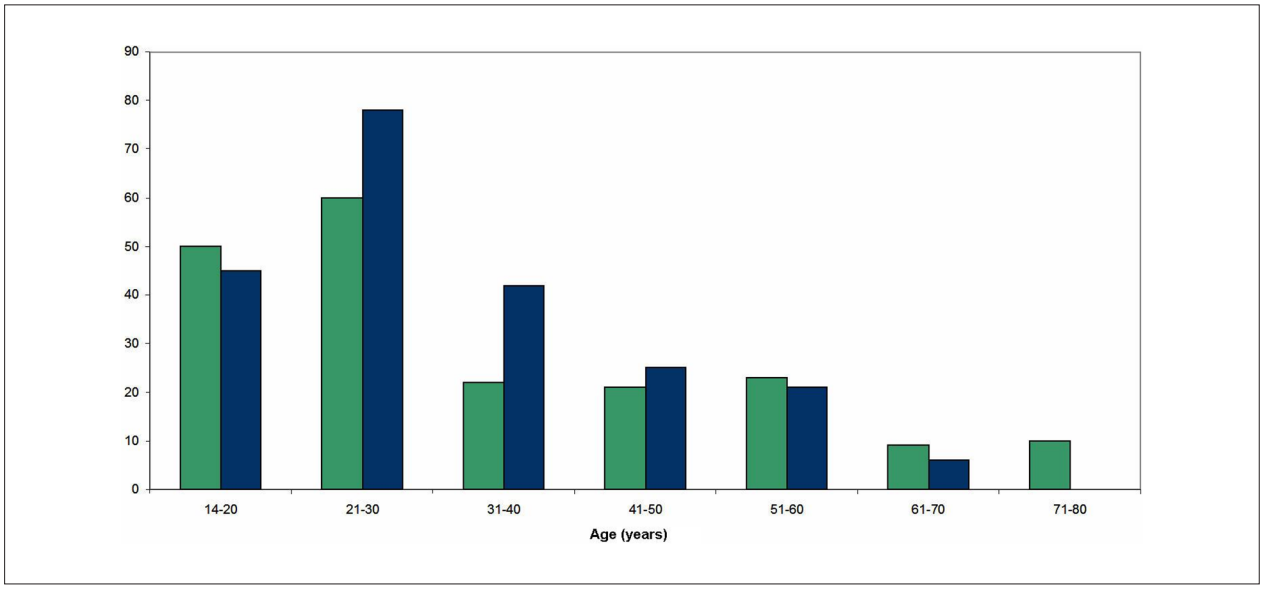

Figure 1 - Number of patients in each age group in G1 (untreated) and G2 (treated).

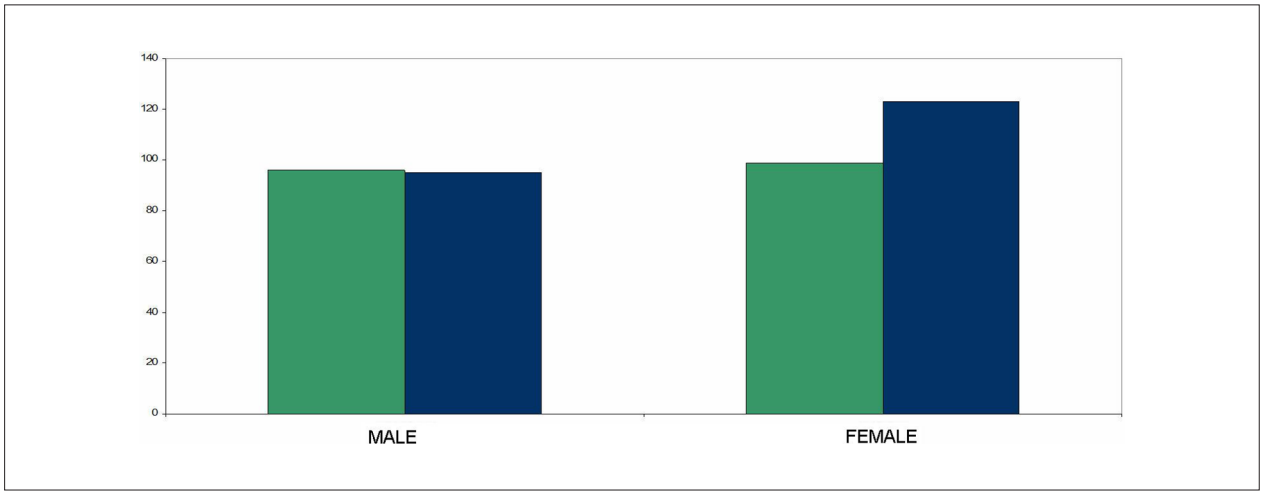

Figure 2 - Number of patients by gender in the G1 (untreated) and G2 (treated).

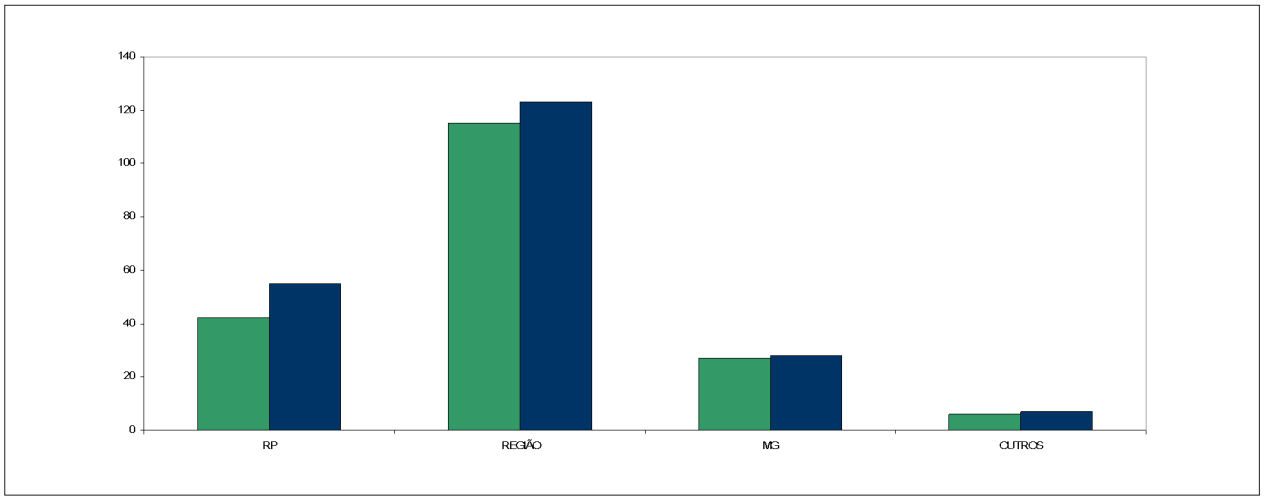

Figure 3 - Place of residence of 413 patients treated as outpatients. RP - Ribeirão Preto; Região - region; MG - Minas Gerais; outros - other states.

valve stenosis (PS). Other diagnoses were:

- Aortic stenosis: 11 (6%), five of them subvalvular;
- Coarctation of the aorta: 8 (4%);
- Ebstein's disease: 6 (3%);
- Atrioventricular septal defect: 5 (2%), two of them in complete form.

Other defects were: corrected transposition of the great arteries, congenital complete atrioventricular block, and single ventricle: 4 patients each (6%); patent ductus arteriosus, bicuspid aortic valve, and patent foramen ovale: 3 patients each (5%). In 7% rare entities, there were:

- Severe pulmonary valve regurgitation; partial anomalous pulmonary venous drainage; and common arterial trunk with severe pulmonary hypertension: 2 patients each.
- Tetralogy of Fallot; Marfan syndrome; Uhl's disease; primary pulmonary hypertension; Takayasu disease; pulmonary arteriovenous fistula; dilated cardiomyopathy; and mitral valve prolapse: 1 patient each (Figure 4).

Of these patients, 148 (75%) had mild lesions that required no treatment; 34 (17%) waited for cardiovascular intervention at the time of the study; 7 (4%) patients had Eisenmenger's syndrome in which surgery was not possible; and 6 patients (4%) refused the proposed surgery.

We observed 95 secondary diagnoses - hypertension: 17 patients (9%); arrhythmia: 10 patients (5%); bicuspid aortic valve and Down's syndrome: 6 patients each (6%); obesity and sequelae of cerebrovascular accident (CVA): 5 patients each (3%); coronary artery disease: 4 patients (2%); depression, chronic lung disease and hypothyroidism: 3 patients each (6%); VSD, dyslipidemia, leukemia, congenital rubella syndrome, Chagas disease, diabetes, and Turner syndrome: 2 patients each (7%). Thalassemia; chronic renal failure; hemophilia; deafness; myocardial infarction; gout; Rendu-Osler-Weber syndrome; aortic regurgitation; bronchial asthma; blindness; pulmonary supravalvar stenosis; hemangioma; stenosis of the esophagus; brain abscess surgery; breast lump; anxiety; Wolff-Parkinson-White syndrome; epilepsy; and AIDS were found in one patient each (5%) (Table 1).

Group 2 (N = 218)

Most patients were in the third (n = 78) and second (n = 48) decades of life, with a progressively lower prevalence in subsequent decades. We observed the following: 123 patients (57%) were aged between 14 and 30 years (Figure 1); 123 (56%) were women and 95 (44%) were men (Figure 2); 55 (25%) lived in the city of Ribeirão Preto; 123 (56%) lived in

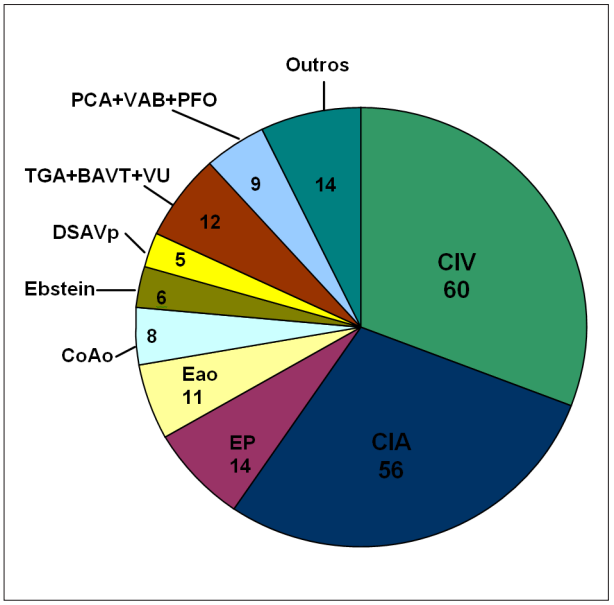

Figure 4 - Main diagnosis and number of patients in 195 untreated individuals. CIV - ventricular septal defect; CIA - atrial septal defect; EP - pulmonary valve stenosis; Eao - aortic valve stenosis; CoAo - coarctation of aorta; DSAVp - partial form of atrioventricular septal defect; TGA - transposition of the great arteries; Bavt - congenital complete heart block; VU - single ventricle; PCA - patent ductus arteriosus; VAB - bicuspid aortic valve; PFO - patent foramen ovale; Outros - others.

Table 1 - Secondary diagnoses in 195 non-operated patients

Hypertension	17	Thalassemia	1
Arrhythmias	10	Chronic renal failure	1
Bicuspid aortic valve	6	Hemophilia	1
Down Syndrome	6	Deafness	1
Obesity	5	AMI	1
Sequelae of stroke	5	Drop	1
Coronary	4	Rendu-Osler-Weber Syndrome	1
Depression	3	Regurgitation	1
Chronic lung disease	3	Asthma	1
Hypothyroidism	3	Amaurosis	1
CIV	2	Pulmonary stenosis	1
Dyslipidemia	2	Hemangioma	1
Leukemia	2	Esophageal stenosis	1
Rubella syndrome	2	Brain abscess	1
Chagas Disease	2	Palpable	1
Diabetes	2	Anxiety	1
Turner syndrome	2	WPW syndrome	1
AIDS	1	Epilepsy	1

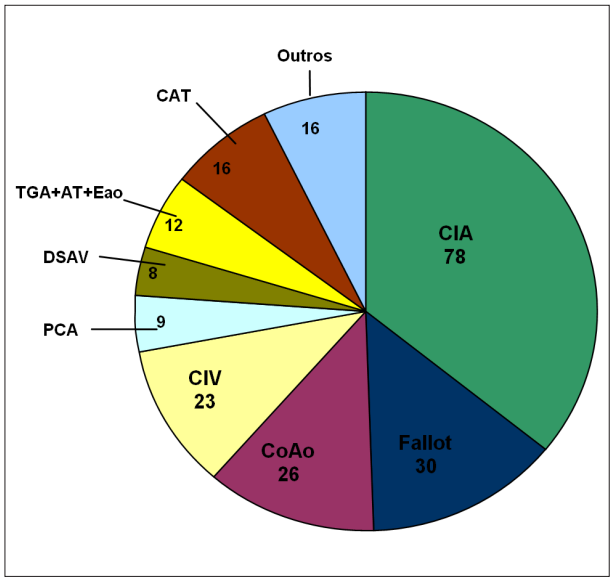

Figure 5 - Main diagnosis and number of patients in 195 treated individuals. Fallot - tetralogy of Fallot; DSAV - atrioventricular septal defect; AT - tricuspid atresia; CAT - interventional catheterization (remainder as Chart 4).

cities of the region; 28 (13%) lived in Minas Gerais; and 7 (4%) in other states. There was no information on the city or state of residence of 5 (2%) patients (Figure 3).

The most common procedures were:

ASD occlusion: 78 patients (36%); repair of tetralogy of Fallot: 30 patients (14%); relief of coarctation of the aorta: 26 patients (12%); VSD occlusion: 23 patients (11%); PDA occlusion: 9 patients (4%); correction of atrioventricular septal defects: 8 patients (4%); in addition to relief of aortic stenosis, surgical intervention in corrected transposition of great arteries, and Fontan palliative surgery for tricuspid atresia: 4 patients each (5%). In 16 patients (7%) the following procedures were performed: Glenn surgery: 3 patients; pulmonary artery banding; aortic reimplantation of the anomalous origin of the left coronary artery from the pulmonary artery; correction of Ebstein disease; Senning operation; and correction of total anomalous pulmonary venous drainage: 2 patients each. Ross procedure, pulmonary commissurotomy, and vegetectomy secondary to endocarditis were performed in one patient each. In 16 (7%) patients, interventional catheterization was performed: pulmonary valvotomy in 10 patients; relief of coarctation of the aorta in 4 patients; and ablation of anomalous bundle in 2 patients (Figure 5). Sixty-nine (32%) patients had been operated on for congenital heart disease in adulthood.

We observed 152 secondary diagnoses: hypertension: 40 (18%); arrhythmia: 18 (8%); pulmonary stenosis: 11 (5%); neuropsychiatric disorders: 10 (5%); small VSD: 8 (4%); bicuspid aortic valve: 8 (4%); obesity: 7 (3%); Down syndrome: 6 (3%); and hypothyroidism: 5 (2%). Pulmonary hypertension, mild aortic stenosis, and coronary artery disease were found in 4 patients each (6%). Mitral insufficiency; liver cirrhosis; pulmonary insufficiency; mitral valve prolapsed; and Eisenmenger syndrome were found in 2 patients each (4%). Diabetes; sequelae of stroke; chronic kidney disease; Williams syndrome; Chagas' disease; breast cancer; congenital rubella syndrome; peripheral arterial obstruction syndrome; Holt-Oram syndrome; mild aortic regurgitation; small ASD; chronic gastritis; Turner syndrome; mild form of Ebstein disease; syphilis; chronic hepatitis; and mild mitral stenosis were found in 1 patient each (8%) (Table 2).

In the untreated group, 79% had VSD; ASD; pulmonary stenosis; aortic stenosis; coarctation of the aorta; and a partial form of atrioventricular septal defect, the most frequent condition being ventricular septal defect (31%). In the treated group, 81% were operated for ASD; tetralogy of Fallot; coarctation of the aorta; VSD; PDA; and atrioventricular septal defect, the most common procedure being ASD occlusion (36%).

Among the 95 secondary diagnoses in non-operated patients, 17 (9%) had hypertension and 10 (5%) had some form of arrhythmia, whereas among treated patients, these figures were 40 (18%) and 18 (8%) of 156 diagnoses, respectively.

Discussion

The clinic and surgery center for pediatric cardiac care at the *Hospital das Clínicas* of the School of Medicine of Ribeirão Preto was established nearly four decades ago. However, the more complex cases started being treated, in greater numbers, in the last twenty years, and a multidepartmental group was established only ten years ago, with a marked increase in neonatal invasive treatment. These patients were followed up in pediatrics and transferred to the cardiology clinic at 16, a practice still in use today. Specialized medical consultation with a specific agenda began about ten years ago (Prof. José

Table 2 - Secondary diagnoses in 218 operated patients

Hypertension	40	Diabetes	1
Arrhythmia	18	Sequelae of stroke	1
Pulmonary stenosis	11	Chronic nephropathy	1
Neuropsychiatric disorders	10	Williams Syndrome	1
Ventricular septal defect	8	Chagas Disease	1
Bicuspid aortic valve	8	Breast câncer	1
Obesity	7	Congenital rubella syndrome	1
Down Syndrome	6	Peripheral arterial obstruction	1
Hypothyroidism	5	Holt-Oram Syndrome	1
Pulmonary hypertension	4	Mild aortic regurgitation	1
Aortic stenosis	4	Small atrial septal defect	1
Coronary heart disease	4	Gastritis	1
Mild mitral regurgitation	2	Turner syndrome	1
Cirrhosis	2	Mild Ebstein's anomaly	1
Pulmonary insufficiency	2	Lues	1
Mitral valve prolapse	2	Hepatitis	1
Eisenmenger Syndrome	2	Mild mitral stenosis	1

Antonio Marin Neto, personal communication), showing the concern of the division of cardiology with these patients. The objective of this study was to obtain a basic clinical profile of the patients seen in the last seven years, a period of increased activity at the clinic, in order to elaborate a mapping of cases as the initial process for future research.

Initially, we noted that most patients were older than 40 years, both in the untreated group (68%) and in the treated group (73%). In both groups, a higher concentration of patients in the third decade of life was observed. These numbers reveal a relatively young population, a fact obviously related to the period of time since the cardiology and pediatric cardiac surgery services became available.

We noted a similar gender proportion among the untreated cases. However, in the treated group, the proportion of women was higher (56%), and this was possibly related to the large number of patients with ASD.

We found that 80% of the patients lived in the region of Ribeirão Preto, particularly in nearby towns within a radius of approximately 200 km, but not necessarily belonging to the regional board. This information is interesting because it may raise questions about the referral pattern suggested by the government authorities and, therefore, the allocation of resources. It should be emphasized that there is a tendency to refer these patients to regional cardiological outpatient clinics, in which usually there is no specialized care for adults with congenital heart disease, thus reducing the possibility of adequate guidance[9].

Among the 195 untreated patients, VSD (31%) and ASD (29%) predominated. Pulmonary and aortic stenosis, coarctation, and complex congenital heart disease were less frequent, and the sample was similar to those of other services[10]. Importantly, 148 (75%) of these cases presented small lesions which permitted the normal development of the patient and did not require specific therapy, and 34 (17%) patients presented lesions of considerable impact and were waiting for cardiovascular intervention at the time of the study. Of these patients, 7 (4%) had Eisenmenger syndrome secondary to the original heart defect, which rendered surgery impossible, whereas 6 (4%) had a significant lesion and rejected the surgery.

Noteworthy among the 218 treated patients is the significant number of ASD occlusion surgeries (36%). This procedure is considered the most common surgery in the nonpediatric population, and it is important to remember the current trend of performing percutaneous occlusion[11]. This defect is often diagnosed in adults[12] and, despite how controversial is its occlusion in the asymptomatic stage[13], most of the cases of "significant impact" are treated with good results[14], especially if the patient is operated before reaching 40 years of age[15]. We found fewer patients who underwent surgery to repair tetralogy of Fallot (14%), coarctation of the aorta (12%), and VSD (11%), and a relative "benignity", as it were, was observed in this case series, despite the recognized need for offering specific guidance to these patients[2]. Noteworthy is the low occurrence of complex congenital heart disease in this group, but it is important to stress that in our institution, most of these patients are still under the care of the pediatric outpatient clinic. In the medium term a progressive increase in the number of these cases is expected, along with their potential complications. An interesting fact to be stressed is that, in this group, 69 (32%) patients had been treated in adulthood. This is a characteristic aspect of the congenital heart disease that has been frequently observed due to the significant rate of reoperations and even late diagnosis, which, in our opinion, justify a specific investigation.

In this study, beside the aspects related to the cardiac defect itself, the secondary diagnoses stand out. Hypertension and arrhythmias were common, along with the aforementioned[16] wide variety of other comorbidities, which indicate the need for multidisciplinary care in a tertiary center. These entities, in addition to requiring specific therapy, may hemodynamically affect the evolvement of the underlying heart disease, as in the case of hypertension and arrhythmias, as well as other conditions such as chronic lung disease and diabetes.

Thus, our sample - which was composed of a slightly greater number of patients who underwent a therapeutic intervention, the majority of them living in the region - may be considered relatively young, with a small preponderance of females in the treated group. ASD and VSD make up the majority of the untreated cases, whereas, among the treated patients, the vast majority had undergone surgical correction of ASD, tetralogy of Fallot, aortic coarctation, and VSD[17]. Hypertension and arrhythmia were relevant in both groups, but the wide variety of other nosological entities was also noteworthy.

The comparison of these data with information from other services in the country is difficult, for publications with these characteristics, which would be extremely desirable, are not available in our country. However, experiences from other outpatient centers that have been published[18,19] allowed for

this type of analysis. Initially, we noted that our population of operated female patients was slightly larger (56%) compared with the studies mentioned above (47% and 49%, respectively), probably due to the large number of patients who underwent ASD occlusion among our cases. Regarding the proportion of non-operated and operated patients, which were very similar in our cases, the figures differ. The study conducted by Gatzoulis et al[18] of the Toronto Hospital shows that 27% of non-operated patients were outpatients, a fact that certainly is related to the large pediatric surgical activity at the institution. In turn, the figures provided by Shirodara et al[19] who reported that 66% of non-operated patients were treated at his clinic, reflected the experience of a smaller district center. Among our cases, in the analysis of the three experiments, we also noticed similarities regarding the main diagnoses, except for a slightly smaller number of patients with systemic obstruction and complex congenital heart disease.

Some interesting studies have attempted to scale the growth prospect of a service for congenital heart disease in adults, indicating that for every 100 thousand live births, 200 new cases will occur[20]. Extrapolating this data to our population, and according to the referral pattern mentioned above, which comprises approximately four million people with an annual rate of 54 thousand live births[21], we estimate an increase of 109 cases per year. These numbers raise concern, because the vast majority of these patients will not be discharged from the outpatient clinic, and a linear increase in the number of clinical visits is expected[22]. To meet this growing demand, human resources and specialized training are needed.

The well known history of pediatric patients with congenital heart disease is usually marked by considerable efforts of the families and the medical community, including administrators of health care resources. These costs are high, especially in relation to complex heart diseases that require reoperation and prolonged hospital stay. The social and psychological consequences of these treatments in the pediatric population can have adverse effects in adults[23]. We believe that these factors should serve as a stimulus for providing an appropriate assistance to adult survivors. Identifying these patients and referring them to specialized centers should be seen as essential measures[24,25], and it is important to emphasize that the vast majority of the performed procedures are palliative, rendering the routine follow-up particularly important.

We believe that the establishment of a congenital heart disease service for adults with guaranteed access and full availability of comprehensive diagnostic and therapeutic resources should be basically mirrored in established institutional models[4] and should serve as an important element for the full reintegration of these individuals in the community. Assistance should be regionally centralized, provided by a trained staff and associated with an active pediatric group which has good relationships with cardiologists and hospitals in the region[25]. The long term follow up of these patients should provide the pediatric surgical team with useful information regarding the effectiveness of interventions for their future practice.

Since the initial reports that specifically addressed congenital heart diseases in adults, numerous contributions have been provided in this area of increasing activity in outpatient clinics. It seems important, in our environment, to establish and integrate regional centers, in order to share experiences, provide support for answering unanswered questions by means of a combination of patient case data collected at the services, and establishing standards for diagnosis and treatment in the various entities. The research development in this area is particularly interesting and necessary in our country, as there is an absolute scarcity of publications on this subject. Some of the more advanced centers have produced information of great value in managing these patients, often by means of multicenter studies[26], which we believe should be a goal to be achieved in our country.

Study limitations

The case series presented do not match the total number of patients in the institution, in the period analyzed. We had difficulties in obtaining information on the earliest cases, but their number is probably small and should not substantially change the results. The annual forecast number of new patients was estimated by considering the regions usually involved in the referral process, but it must be remembered that this referral is not compulsory, and this number may vary.

Potential Conflict of Interest

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

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There were no external funding sources for this study.

Study Association

This study is not associated with any post-graduation

References

1. Garson A Jr, Allen HD, Gersony WM, Gillette PC, Hohn AR, Pinsky WW, et al. The cost of congenital heart disease in children and adults: a model for multicenter assessment of price and practice variation. Arch Pediatr Adolesc Med. 1994; 148 (10): 1039-45.
2. Warnes CA. The adult with congenital heart disease: born to be bad? J Am Coll Cardiol. 2005; 46 (1): 1-8.
3. Brickner ME, Hillis LD, Lange RA. Congenital heart disease in adults: first of two parts. N Engl J Med. 2000; 342 (5): 256-63.
4. Niwa K, Perloff JK, Webb GD, Murphy D, Liberthson R, Warnes CA, et al. Survey of specialized tertiary care facilities for adults with congenital heart disease. Int J Cardiol. 2004; 96 (2): 211-6.
5. Atik E, Atik FA. Cardiopatias congênitas na idade adulta: considerações acerca da evolução natural e da evolução de pacientes operados. Arq Bras Cardiol. 2001; 76: 423-9.
6. Mesquita SF, Snitcowsky R, Lopes AA. Estrutura e função ventricular direita como possíveis determinantes do resultado cirúrgico após 30 anos de

correção de tetralogia de Fallot. Arq Bras Cardiol. 2003; 81 (5): 453-7.

7. Atik E, Atik FA. Tétrade de Fallot: qual o real benefício da correção operatória na idade adulta? Arq Bras Cardiol. 2004; 83 (4): 278-9.
8. Negrão EM, Brandi IV, Nunes SV, Távora DGF, Nakayama M, Beraldo PSS. Forâmen oval patente e acidente vascular cerebral isquêmico em jovens: associação causal ou estatística? Arq Bras Cardiol. 2007; 88 (5): 514-20.
9. Hunter S. Management of adults with congenital heart disease. Heart.1997; 78 (1):15.
10. Miyague NI, Cardoso SM, Meyer F, Ultramari FT, Araújo FH, Rozkowski I, et al. Estudo epidemiológico de cardiopatias congênitas na infância e adolescência: análise de 4538 casos. Arq Bras Cardiol. 2003; 80 (3): 269-73.
11. Jones TK, Latson LA, Zahn E, Fleishman CE, Jacobson J, Vincent R, et al. Results of the U. S. multicenter pivotal study of the Helex septal occluder for percutaneous closure of secundum atrial septal defects. J Am Coll Cardiol. 2007; 49 (22): 2215-21.
12. Kaplan S. Natural adult survival patterns. J Am Coll Cardiol. 1991; 18 (2): 319-20.
13. Oakley CM. Does it matter if atrial septal defects are not diagnosed in childhood? Arch Dis Child.1996; 75 (2): 96-9.
14. Perloff JK, Child JS. (editors). Congenital heart disease in adults. Philadelphia: WB Saunders; 1991.
15. Jemielity M, Dyszkiewicz W, Paluszkiewicz L, Perek B, Buczkowski P, Ponizynski A, et al. Do patients over 40 years of age benefit from surgical closure of atrial septal defects? Heart. 2001; 85 (3): 300-3.
16. Perloff JK. Adults with surgically treated congenital heart disease: sequelae and residua. JAMA.1983; 250 (15): 2033-6.
17. Perloff JK, Warnes CA. Challenges posed by adults with repaired congenital heart disease. Circulation. 2001; 103 (21): 2637-43.
18. Gatzoulis MA, Hechter S, Siu SC, Webb GD. Outpatient clinics for adults with congenital heart disease: increasing workload and evolving patterns of referral. Heart. 1999; 81 (1): 57-61.
19. Shirodaria CC, Gwilt DJ, Gatzoulis MA. Joint outpatient clinics for the adult with congenital heart disease at the district general hospital: an alternative mode of care. Int J Cardiol. 2005; 103 (1): 47-50.
20. Wren C, O'Sullivan JJ. Survival with congenital heart disease and need for follow up in adult life. Heart. 2001; 85 (4): 438-43.
21. Ministério da Saúde. Sistema de Informações sobre nascidos vivos (SINASC) [Acesso em 2009 ago 10]. Disponível em: http://portal2.saude.gov.br
22. Somerville J. Grown-up congenital heart disease: who knows? Who cares? Cardiologia.1990; 35 (11): 893-8.
23. Hamburgen ME. Psychosocial concerns and life-style. Congenital heart disease after childhood: an expanding patient population. J Am Coll Cardiol. 1990; 18 (2): 333-4.
24. Jonsson H, Ivert T. Survival and clinical results up to 26 years after repair of tetralogy of Fallot. Scand J Thorac Cardiovasc Surg. 1995; 29 (2): 43-51.
25. Webb GD. Challenges in the care of adult patients with congenital heart defects. Heart. 2003; 89 (4): 465-9.
26. Khairy P, Hosn JA, Broberg C, Cook S, Earing M, Gersony D, et al. Multicenter research in adult congenital heart disease. Int J Cardiol. 2008; 129 (2): 155-9.