SPECIAL ARTICLE

Rev Bras Cir Cardiovasc 2012;27(3):457-62

A reflection on the performance of pediatric cardiac surgery in the State of São Paulo

Uma reflexão sobre o desempenho da cirurgia cardíaca pediátrica no Estado de São Paulo

Luiz Fernando Caneo[1], Marcelo Biscegli Jatene[2], Nelson Yatsuda[3], Walter J Gomes[4]

DOI: 10.5935/1678-9741.20120076

RBCCV 44205-1407

Descriptors: **Congenital heart disease. Congenital heart defects/surgery. Cardiac surgical procedures.**

Descritores: **Cardiopatias congênitas. Cardiopatias congênitas/ cirurgia. Procedimentos cirúrgicos cardíacos.**

INTRODUCTION

The prevalence of congenital heart disease is 9 children per 1000 births [1] and is estimated to rise to 28,846 new cases of congenital heart disease in Brazil each year. Around 20% of these cases, the defect resolution is spontaneous, being related to less complex defects and discrete hemodynamic repercussion [2]. Based on these parameters, the average need of cardiovascular surgery in congenital heart disease in Brazil is approximately 23,077 procedures / year, as part of this estimate, besides new births with congenital heart disease, cases of reoperation in patients operated during evolution. In 2002, 8092 patients were operated, which shows a gap of 65%, with the highest rates in the North and Northeast regions of Brazil (93.5% and 77.4%, respectively) and lowest in the South and Midwest regions (46.4% and 57.4%, respectively) [2]. Early treatment of congenital heart disease modifies the natural history, avoiding early death, substantially decreasing hospitalizations caused by complications of the disease, and also providing better quality of life. It is known that 50% of patients with congenital heart disease should be operated in the first year of life. Thus, 11,539 new procedures are necessary every year in Brazil. As the public sector absorbs 86.1% of the cases, it is estimated a deficit of 80.5%. The situation is most critical in the North and Northeast, with a deficit of 97.5% and 92%, respectively [2].

1. Department of Pediatric Cardiovascular Surgery of the Brazilian Society of Cardiovascular Surgery, Physician Assistant, Division of Cardiovascular Surgery, Heart Institute of the Medical School Clinical Hospital, University of São Paulo (INCOR-HCFMUSP), Sao Paulo , SP, Brazil.
2. Department of Pediatric Cardiovascular Surgery of the Brazilian Society of Cardiovascular Surgery, Director of Pediatric Cardiac Surgery Unit INCOR-HCFMUSP, São Paulo, SP, Brazil.
3. Master's Student of the Professional Master Course in Collective Health, Graduate School of Medical Sciences of Santa Casa de São Paulo, São Paulo, SP, Brazil.
4. President of the Brazilian Society of Cardiovascular Surgery, São Paulo, SP, Brazil.

Correspondence Address:
Luiz Fernando Caneo
44 Dr. Eneas de Carvalho Aguiar Avenue, - São Paulo, SP, Brazil – Zip code: 05403-900
E-mail: caneo@mac.com

Article received on July 1st, 2012
Approved on July 25th, 2012

Abbreviations, Acronyms & Symbols	
ICD	International Classification of Diseases
DATASUS	Unified Health System Database
HDI	Human Development Index
WHO	World Health Organization
PAHO	Pan American Health Organization
GPD	Gross Domestic Product
RIPSA	Interagency Network of Information for Health
SEADE	State System of Data Analysis
SES-SP	State of São Paulo Health Departament
IMR	Infant mortality rate
ICU	Intensive Care Unit

Brazil is a country of continental dimensions with many regional differences. Establishing objective parameters to evaluate our quantitative and qualitative results that can be compared to those of countries where child care with congenital heart disease has proved more efficient is a big challenge. Considering the state of São Paulo as a reference, we expect to be a country economically and demographically comparable, drawing a parallel, in relation to the quality of care for patients with congenital heart disease requiring surgery.

Recently, publications of the magazine "The Economist", the Brazilian states were compared to countries as to its individual gross domestic product (GDP) and its GDP *per capita*. Using these criteria, the state of São Paulo amounted to Poland, in other words, a country with per capita income greater than U.S. $ 12,276, which according to the World Bank is classified as part of the group of countries with high income per capita. São Paulo has always been considered as one of the most developed and prosperous state of the country, and although it occupies the first position in this publication, it is in second place, losing only to the Federal District. While the Federal District has a lower GDP, the GDP *per capita* is compared to that of Portugal and greater than that of Poland.

When we use other indicators to assess our development, the observed result reinforces our position equal to developed countries. Whereas, for example, the Human Development Index (HDI). Sao Paulo is in third place ranking among Brazilian states, where its index is 0.82, again very close to that of Poland is 0.81. The Federal District is in first place with a score of 0.844, followed by Santa Catarina in second with 0.822. Despite occupying the third position, São Paulo had an increase of only 5.4% of HDI in the 90's and, therefore, dropped from second to third place.

Some Brazilian states are comparable to many European countries in terms of economic and financial analysis. The State of São Paulo, in turn, can be considered a wealthy state, economically developed and compared to a first world nation. The economic growth of our country has been widely publicized and celebrated in diverse information sources locally and internationally.

If we are economically occupying a rather optimistic scenario, how are we behaving in the care of children with heart disease? There are countless indicators that we could use in this assessment, but we would like to call attention to the infant mortality rate and its decrease observed in the State of São Paulo, which was published recently by the State System of Data Analysis (SEADE) in its bulletin number 6, in August 2011. The infant mortality rate (IMR - which corresponds to the ratio between the numbers of deaths of children younger than one year of age per thousand live births in the population residing in a given geographic area, the current year) expected for a country with income exceeding USD 12.276 is 6 per thousand.

The observed rate in São Paulo in 2010 was 11.9 per thousand, 5% lower than that recorded in 2009 (12.5 deaths per thousand live births). Comparing it with those of later years, it is observed that the IMR decreased by 30% compared to 2000 (17.0 per thousand) and 62% compared to 1990 (31.2 per thousand). Although higher than expected for regions with the same GDP per capita and with the same level of economic development, this result reaffirms the position of São Paulo as one of the states with lower risk of infant death in Brazil in accordance with the Interagency Network Information for Health (RIPSA), formalized by Ministerial Ordinance (Ordinance No. 2.390/GM, Ministry of Health), and participant in term of cooperation with the Pan American Health Organization (PAHO) and World Health Organization (WHO) responsible for standardization and dissemination of official information on health in the country.

If we go deeper into the analysis of these numbers, we can understand the reason for this difference. In a more detailed analysis of these data, we identified that among the causes of infant mortality according to the chapters of causes of death in ICD-10 (WHO, 1998), only two of them - perinatal and congenital malformations - are currently responsible for 80% of deaths in Sao Paulo. Perinatal causes, those related to problems in pregnancy, at delivery and at birth, compared to 2000, decreased approximately 30% and were primarily responsible for the decrease in infant mortality in the period (63% of the total reduction). On the other hand, infant deaths due to congenital malformations presented in the same period were the lowest rates - only 12%. Thus, their share of total infant deaths increased from 17% (2000) to 21% (2010).

Interestingly, congenital cardiovascular malformations are the leading cause of death in this group. Assuming that congenital heart disease can be treated, and it can also be considered a preventable death, the adequate treatment of this population will result in significant reduction in IMR. Thus, the problems of public health in the state of São

Paulo, as well as the rich and developed countries, are not restricted to basic health and are also problems arising from complex specialties such as cardiology and pediatric cardiac surgery. To exemplify this statement, congenital heart defects are responsible for the decline of 59% of all deaths in the United States in the years 1970 to 1997, with better results in their treatment [3].

When we analyzed the deaths under 1 year of age, according to preliminary data from the Database Health System (DATASUS), there were 7155 deaths in 2010, of this total, 1490 (21% of IMR) were by birth defects as the underlying cause of deaths, congenital heart defects as the most common malformations, occurring as the underlying cause in 607 deaths (40% of malformations). Of the total infant deaths, we observed in 1012 (14.2% of IMR) had an International Classification of Diseases (ICD) of CHD in any line of cause on the death certificate (Part I or II of the causes of death in the death certificate).

The state of São Paulo is recognized as one the major pediatric cardiac surgery centers in the country with 12 services, 6 of them in the city of São Paulo and 6 in the state. In the year 2010, 600 surgeries were performed in the State of Sao Paulo in children under 1 year of age (160 newborns and 440 under 1 year of age), with an average hospital mortality of 14%, neonates (until 28 days of age) presented a rate of 26.8% and 9.32% in children who were 29 days to 1 year old (data from the Ministry of Health of the State of Sao Paulo - SP-SES). The demand for this population is 2,693 surgeries annually.

Whereas about 50% of these children require some type of surgical procedure during the first year of life, the demand is 1,300 procedures in this age group, and at least 80% by the public health system. Whereas the total number of surgeries performed in children younger than 1 year of age in 2010 was 600, our research results show a deficit of 54% in this age group.

Poland has a current population exceeding 38 million, very similar to Sao Paulo. In 2010, Poland presented an IMR of 6.8 per thousand, very close to that expected for their economic condition. As previously noted, the demand for cardiac surgery varies with the number of live births. Taking into consideration this fact, we can draw a comparison with the state of São Paulo, with regard to the need for pediatric cardiac surgery population and the number of procedures performed. We should use an indicator to assess the number of live births per thousand inhabitants in the population of a given geographic area, in the current year (birth rate).

It was noticeable that Poland had fewer births (birth rate: 9.5 births/1000 inhabitants or fertility rate: 1.23 births/woman) than the state of São Paulo (birth rate: 13.3 births/1000 inhabitants or fertility rate: 1.78 births/woman) in 2010. Moreover, the absolute number of surgeries in children aged less than 1 year operated in Poland was superior to that performed in the State of São Paulo (1646 children, 637 infants with neonatal mortality and 1009 newborns with 8.7 and 4.7% respectively) - data from the National Report of Poland, EACTS Congenital Database, and sent by Dr. Tobota and Bohdan Maruszewski in the same period. Considering birth rates, population need for surgery in the first year of life and number of surgery performed in 2010, Poland performed 100% of its needs, while the state of São Paulo only 50%. Besides the lower number of procedures and insufficient demand by population, surgical outcomes when compared to Poland, regardless of the degree of complexity, but related to the same age group, are inferior to that country (in-hospital mortality observed in the State of Sao Paulo services: 26.68% and 9.3%, 8.7% and 4.7% in Poland for neonates and infants, respectively).

In attempting to explain this scenario, the first impression is that lack of access in our state, and perhaps increase the number of centers would be a solution that will quickly come up. The solution, however, does not seem to be an increase in the number of centers and, even those that already exist need to produce what is expected of them. When they reach their limit, we can consider increasing the number of centers. This can be seen when analyzing the production of state services (SES-SP report), many of them do not achieve the minimum number specified by ordinance 210 which directs its accreditation. As for the results, recent studies show that they depend on many factors, not only technical, but also the number of surgeries performed at the center, organizational structure and technology among others. Pediatric cardiac surgery has much in common with high-tech systems, where performance and results depend on individual, technical and organizational factors, and their interactions. Further analysis should be performed to understand this scenario, since they are multivariate factors.

Considering the importance of congenital heart disease in the composition of IMR in richer countries, improving care in this specialty will cause a major impact in reducing it. So that we can achieve the IMR indexes in Sao Paulo equivalent to indexes in Poland, and the so-called developed countries, it is essential, in addition to improving prenatal diagnosis and delivery care, increasing the number of surgical procedures in congenital heart disease and improving the current immediate results.

Ensuring children's access to cardiac care network specialist and improvement of surgical outcomes of specialized services are fundamental in order to have a significant decrease in infant mortality in the State of São Paulo. In states as ours, the proper treatment of congenital heart disease, ensuring access to those that need it, encouraging centers qualified for this assistance, ongoing training of the staff involved and adequate investment have become an important public health problem.

Although expensive, highly specialized and complex, the development of a well-structured pediatric cardiac surgery today occupies an important role in public health policy, particularly in states that have reached a high degree of economic development. The difficulty of access is just one of the problems generated by poverty and inequality where pediatric cardiac surgery is not considered a priority and it cannot be done if there is lack of money or infrastructure [4]. If some states require larger number of centers, others will benefit from improvements in existing centers.

Anyway, the child care network of cardiac patient needs to be rethought and restructured in order of priority. There is no doubt that the lack of adequate funding, lack of specialized centers in certain regions, lack of trained personnel and a continuing education and the organization of the network play a key role in this scenario. With regard to the funding, we believe that it is not a simple increase in their values that count, but the form of management. We recently observed that while more money has been allocated to pediatric cardiac surgery in recent years, had little impact on increasing the number of surgeries.

Using Poland as an example, how to explain that the *per capita* health expenditure in Poland, similar to the State of São Paulo (6.12% versus 5.94% of GDP in USD - 1997, World Bank 2002), has best results (number of surgeries by population demand, immediate surgical results, among other indicators analyzed). The money allocated by the federal government does not always get to the pediatric cardiac surgery service the way it should. There are numerous reasons, but perhaps the most important one is that there is no discrimination of cardiovascular pediatric surgery from cardiovascular surgery in general in hiring service between the provider and the local government.

Few centers have a specific contract for pediatric cardiac surgery, which makes the financial ceiling be allocated according to institutional and personal interest in cardiac surgery in general, including pacemaker and hemodynamics. Often, the budget of pediatric cardiac surgery procedures is intended for less complex, lower cost or higher institutional or personal interests. The remuneration differentiated according to the complexity of the procedure appears to be yet another major problem, especially for those that face the more complex cases.

The fact that almost no differentiation is made in the payment procedure according to its complexity punishes the referral center that is dedicated to more complex cases and discourages the growth of the number of procedures in neonates and infants, especially in the higher complexity scores. Some international studies have shown that there is a linear relationship between the complexity and the procedure costs [5]. This was also observed in our environment [6], where the group using the procedures by means of classification by Aristotle Basic Score [7] observed that patients with higher rating than twice the required length of stay in Intensive care unit (ICU). These same patients had higher number of examinations, diagnostic tests and procedures. The presence of infection before the procedure, regardless of age group and complexity, triples the procedures costs. Postoperative infection increases at three times the cost of surgery in neonates and adolescents and doubles the cost in more complex patients. If everything does not improve, probably the high complexity will be penalized by the inefficiency of the system.

Low pay, high cost and high complexity make few centers perform over 250 cases per year in Brazil, which is considered an ideal number to obtain adequate results in congenital heart surgery, in order to have good surgical results and low mortality [8]. Few pediatric cardiac surgery centers are located in children's hospitals, and the number of personnel trained in this area of knowledge is very small.

In an interview conducted among Brazilian pediatric surgeons [9], only 29% of surgeons who were considered pediatric surgeons (since there is no such area of interest in the Brazilian cardiovascular surgery) stated that they are qualified to perform any type of procedure, regardless of the child's age.

Although the accuracy and technical quality of surgery have a role in postoperative survival of newborns and infants, they add up to the early diagnosis, surgical center volume, presence of very well trained interdisciplinary skilled labor, advanced technology and adequate infrastructure to the complexity. Leadership, technical skills and techniques are also not necessary to solve these problems - a puzzle of many challenges - especially in neonatal surgery, which, despite some exceptions, remains a major problem in most developing countries. Complexity requires complexity: less and less in relation to neonatal surgery! [10].

The individual contribution of Brazilian surgeons in pediatric cardiac surgery is quite remarkable, since the Jatene Operation for transposition of the great arteries and also the Cone Operation, for the correction of tricuspid regurgitation in Ebstein's disease. It is undisputed the technical quality of our surgeons. However, as seen previously in a complex system, individual technical skills alone are not responsible for the outcome. The results of surgery depend on high complexity of the entire hospital system and its interaction with the technically and non-technically human capital (cognitive and noncognitive).

Changing our current system, centered on the individual ability of the person to an interdependent and interdisciplinary health system, with well-established policies, centered on quality, patient safety and sustainability must be our goal. To do so, establishing fair and adequate funding, education and training, continuous

monitoring and objective results with the active participation with the government agencies is fundamental.

After comparing Sao Paulo with Poland, we noted that despite the being equal in some aspects, we also have differences, and there is no doubt that, if we identify those differences, we can achieve excellence in pediatric cardiac surgery in this country of inequalities. Finding what is common in our problems and concentrate on solving them can be the best solution (*"We all do better when we work together. Our differences matter, but our common humanity matters more." President Clinton*.)

Today, congenital heart disease already occupies a large role in public health in some Brazilian states, and will certainly occupy in the near future an important role in other areas. If we solve some common ground, surely we will be preparing for all our problems to be are solved in a gradual escalation of priorities.

"The most important thing I've learned in government is that you cannot propose that anything will work in Brazil as a whole."

Vilmar Faria

Among the various actions required at this moment, we chose some important and common ones in our diversity:

• Improve access to pediatric cardiac surgery centers:

- to improve children's access to cardiac centers;
- Extend the productive capacity and qualify of existing centers;
- Open new centers in underserved regions;
- Plan and execute the policies related to cardiology and pediatric cardiac surgery in an organized way, with the support of well-established centers, respecting geographical distances, with the active participation of society with government agencies, through its technical councils and also taking into account regional needs;
- Implement policies that increase the capacity of the health system in diagnosing congenital heart defects, especially during ante-natal period.

• Improve the financing of Cardiology and Pediatric Cardiac Surgery

- Find a new way to secure funding for pediatric cardiac surgery through a review of existing contracts, forms of transfer and adequate compensation, respecting the complexity. The essence of this proposal is that if they get the budget for pediatric heart surgery is effectively applied to it and to its dedicated service.

• Improve database and promote quality management by:

- Create the culture of management by objective data, benchmark, set quality standards, either through the creation of specific database and / or use existing database.

• Establish continuing education programs:

- Establish training programs in different health care professions involved with the care of children with heart disease. Establish training centers along with the other scientific bodies, both in the curriculum discussion and also in mainstream education and training of specialized teams.

Along with the increase observed in our current economic environment, the complexity of our specialty, if well balanced, should put us back in a prominent position on the stage of cardiology and pediatric cardiac surgery worldwide.

From a regional perspective, the services of pediatric cardiac surgery in São Paulo have been meeting on a regular basis, along with the state government, through representatives of SES-SP to discuss, plan and implement actions to improve the network of cardiac care to children in this region. Recently, constituted by a Technical Board, as provided by ordinance MS 210 [11,12], where representatives of the Department of Pediatric Cardiovascular of the Brazilian Society of Pediatrics and the Brazilian Society of Cardiology, the State Department and the Local Department of Health promote discussions based on objective data validated by executors services, solutions to problems raised by managers and difficulties pointed out by the Services.

All this effort, although recent, makes us aware of the strengths, weaknesses, opportunities and threats to all members of the complex network of public health, by a consensus and collective form. Hopefully, in the coming years, our service network, today pointed to the disability and known by all of us, can be compared to those countries that occupy a prominent position on the world stage. Likewise, we hope that the experience of our State will contribute with other Brazilian states, in the sense that solutions to complex problems depends on the joint efforts of all sides of the issue.

Promoting improvements in public health care to children with heart disease is not an isolated problem of the government, and perhaps we should close to this issue, along with society in general, to reach and an improvement in our system.

Thanks

The authors would like to thank Dr. Bohdan Maruszewski and Dr. Zdzislaw Tobota, responsible for EACTS Congenital Database, the data and information related to Pediatric Cardiac Surgery in Poland and Dr. Rodolfo A. Neirotti and Dr. Fabio B. Jatene, by reviewing and commenting on the text. They would also like to

emphasize the unconditional effort the Sao Paulo State Department of Health, along with representatives of heart surgery services in the State of São Paulo are making, in order to find the solutions necessary to modify the current scenario here pointed.

REFERENCES

1. Pinto Jr VC, Daher CV, Sallum FS, Jatene MB, Croti UA. Situação das cirurgias cardíacas congênitas no Brasil. Rev Bras Cir Cardiovasc. 2004;19(2):III-VI.

2. Pinto Jr VC, Rodrigues LC, Muniz CR. Reflexões sobre a formulação de política de atenção cardiovascular pediátrica no Brasil. Rev Bras Cir Cardiovasc. 2009;24(1):73-80.

3. Lee K, Khoshnood B, Chen L, Wall SN, Cromie WJ, Mittendorf RL. Infant mortality from congenital malformations in the United States, 1970–1997. Obstet Gynecol. 2001;98(4):620-7.

4. Neirotti, R. Paediatric cardiac surgery in less privileged parts of the world. Cardiol Young. 2004;14(3):341-6.

5. Sinzobahamvya N, Kopp T, Photiadis J, Arenz C, Schindler E, Haun C, et al. Surgical management of congenital heart disease: correlation between hospital costs and the Aristotle complexity score. Thorac Cardiovasc Surg. 2010;58(6):322-7.

6. Trindade E, Jatene M, Caneo LF, Tanamati C, Riso AA, Abuchaim D, et al. Five-years follow-up of congenital heart surgery at the Heart of the Clinics Hospital/São Paulo Medical School, InCor-HC-FMUSP: HTAi 2010. Disponível em: http://www.htai2011.org/Sessoes_Orais2.asp Acesso em: 15/6/2012 In: 8th Annual Meeting HTAi; Rio de Janeiro, 2011.

7. Lacour-Gayet F, Clarke D, Jacobs J, Gaynor W, Hamilton L, Jacobs M, et al; Aristotle Committee. The Aristotle score for congenital heart surgery. Semin Thorac Cardiovasc Surg Pediatr Card Surg Annu. 2004;7:185-91.

8. Daenen W, Lacour-Gayet F, Aberg T, Comas JV, Daebritz SH, Di Donato R, et al; EACTS Congenital Heart Disease Committee. Optimal structure of a congenital heart surgery department in Europe. Eur J Cardiothorac Surg. 2003;24(3):343-51.

9. Pinto Jr VC. Avaliação da política nacional de atenção cardiovascular de alta complexidade com foco na cirurgia cardiovascular pediátrica [dissertação de mestrado]. Fortaleza: Universidade Federal do Ceará; 2010.

10. Neirotti R. Access to cardiac surgery in the developing world: social, political and economic considerations – FAC – Federación Argentina de Cardiologia – In: 5th Congress of Cardiology on the Internet – 5th Virtual Congress of Cardiology – QVCC – Argentina; 2007.

11. Portaria nº 1169/GM em 15 de junho de 2004. Institui a Política Nacional de Atenção Cardiovascular de Alta Complexidade, e dá outras providências. Diário Oficial, seção 1, n. 115, p.57, 2004.

12. Portaria no 210 SAS/MS de 15 de junho de 2004. Serviços de cirurgia cardiovascular pediátrica. Diário Oficial, seção 1, n. 117, p.43. 2004.