Reflexions about formulation of politics for attention to cardiovascular pediatrics in Brazil

Reflexões sobre a formulação de política de atenção cardiovascular pediátrica no Brasil

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Abstract

The authors discuss the different moments of the National Policy of High-complexity Cardiovascular Care, focusing on the attention to Cardiovascular Pediatrics. This process begun with the attempt to meet the local needs, but, very soon, became a national matter due to the verification of a significant shortage in the attention given to patients with congenital cardiovascular diseases. In 2002 the shortage of procedures in these cases was around 65%. The participation of different agents from the civil society and the Government will be demonstrated regarding the formulation of the policies directed to the attention to cardiovascular pediatrics. Some authors are cited during the discussion to base each moment of the process. The National Policy of High-complexity Cardiovascular Care was regulated on June 15th, 2004, through the Ministerial Directive No. 1169/GM as well as the Pediatric Cardiovascular Surgery, on the same date, through the Ministerial Directive No. 210 SAS/MS. The importance of the civil society participation in the elaboration of the public social politics is emphasized. The intervention of agents who experience the day-to-day difficulties is of the utmost importance to the better knowledge of questions involving the social area.


Resumo

Este artigo discute os vários momentos da formulação da Política Nacional de Atenção Cardiovascular de Alta Complexidade, tendo como foco a atenção cardiovascular pediátrica. Processo iniciado pela necessidade de atender demandas locais, passa a ter dimensões nacionais pela constatação do déficit de atendimento aos portadores de cardiopatias congênitas (CC). Em 2002, a deficiência de procedimentos no Brasil era de 65%. Demonstrar-se-á a participação de vários agentes, da sociedade civil e do público.


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Critical in the North and Northeast, with rates of 97.5% and 92% respectively [2].

Rheumatic fever, a disease with universal distribution, but with marked difference in the incidence and prevalence rate among different countries, is the main cause of acquired heart disease in children and young adults in developing countries. Such disease affects more often patients aged from five to 15 years. According to the epidemiological model of the World Health Organization (WHO), and according to the latest census of the Brazilian Institute of Geography and Statistics (IBGE), is estimated that in Brazil occurs annually about ten million streptococcal tonsillitis, totaling 30,000 new cases of rheumatic fever, of which 15,000 evolve with carditis [3].

Despite the critical situation showed by these data, the fact is that until June 2004, pediatric cardiovascular surgery was not regulated in Brazil.

PEDIATRIC CARDIOVASCULAR SURGERY - BRIEF HISTORY

The first correction of the persistent ductus arteriosus was successfully performed in 1938, by Dr. Robert E. Gross, in the United States. Surgical correction of rheumatic mitral valve stenosis back to May 20, 1923, when Elliot Carr Cutler and Samuel Levine, using tenotomy, successfully performed a transventricular mitral commissurotomy in a 12-year-old patient, at Peter Bent Brigham Hospital of Harvard Medical School. Open heart surgery can be considered one of the most important medical advances of the twentieth century. It is undeniable that this fact deserves great importance, especially when considering that the first open heart surgery was successfully performed only in 1952. It was performed when Dr. F. John Lewis corrected an interatrial communication of 2 cm in diameter, under direct vision with interruption of the cava flows and body moderate hypothermia in a five-year-old girl, at the Hospital of the University of Minnesota (USA).
On May 6, 1945, Joaquim Azarias de Britto performed the first ligation of patent ductus arteriosus at the Souza Aguiar Hospital, in Rio de Janeiro. In November 1948, Arthur Domingues Pinto, in Santos, performed the first Blalock-Taussig surgery in Brazil. On 24 June 1950, he operated the first case of aortic coarctation. In 1951, Euryclides de Jesus Zerbini performed at the Clinics Hospital of São Paulo, the first digital mitral commissurotomy. In 1954, Margutti published the first cases of correction of interatrial communications. On November 12, 1956, Hugo Felipozzi performed the first surgery using cardiopulmonary bypass in Brazil, for correction of an atrial septum defect [4,5].

Since the first procedure up to now, the diagnosis has been improving and currently may be performed so even by intratruncal approach. Also, surgical techniques that approach both the simplest defects and even heart replacement have been improved; drugs able to manage safely the anesthesia and the postoperative, and appropriate technologies for pediatrics have been developed, such as respirators, monitors, orthoses, prostheses, and even artificial heart and, especially, multidisciplinary professionals are trained.

It has been eight decades of intensive work to provide to the speciality conditions for offering quality of life for those undergone treatment of congenital heart diseases.

THE RECOGNITION OF OBSTACLES

In this topic and along the text will be reported: the national dimension struggle, the creation of the Pediatric Cardiovascular Surgery Department (DCCVPed) and the preparation of National Policy of High-Complexity Cardiovascular Care, as experienced by the first author of this study.

During the 1990s, in Fortaleza, there was intensive work to structure a pediatric cardiovascular surgery service to meet the demands unsustainable at that time. The mobilization of health professionals, cardiac patients’s family members and the press, opened space for discussion with the Public Administration, which had its most important moment at a symposium at the Sociedade Cearense de Cardiologia on September 11, 1998, with the presence of representatives of Health Secretaries of Ceará State and Fortaleza City, hospital directors, representatives of the Public Prosecution, pediatric cardiologists and cardiovascular surgeons, which made possible the accomplishment of part of the project of establishment of the Department of Pediatric Cardiovascular Surgery of the Messejana Hospital at Fortaleza-CE.

In March 2000, the facilities for the sector were opened, excepting the Postoperative Pediatric Intensive Care Unit. Political conflicts - based on reserved positions within the service - led to the dismissal of surgeons and cardiopediatrians, episodes repeated twice, in May 2000 and June 2001. The lack of satisfaction due to not achievement of the whole project and the not meeting of the demand led the establishment of a new service in the private sector.

At that time, the State Secretary of Health, Dr. Anastácio Queiroz, showed interest in helping but affirmed that resources would not be available to accomplish this initiative. As official proposal, if a state over-cap fund may achieved, or that is, a new fund from the Ministry of Health (MH), the agreement could be accomplished. During the 29th National Congress of Heart Surgery - Natal, RN, April, 2002 – he had the opportunity to explain the difficulties to the MH representative, Dr. Alberto Beltrame, which signaled the possibility of - in case of national reaching – releasing of resources by the Ministry of Health, by means of collective effort, as an usual practice of the Health Minister of that time, José Serra.

This initiative was supported by many, however, criticisms to this model were immediate because it did not treat the problem completely. There were mobilization of regional societies and the Brazilian Society of Cardiovascular Surgery (BSCVS), in order to prepare a list of each federated unit was interested in participating the program.

In the last quarter of that year, was released funds to meet demands from Brazilian society. With our goal achieved, and in the hope of fulfilling the agreement for the service accreditation, a new meeting was scheduled with the Secretary of State for Health, by experiencing a surprise of a new obstacle. No one could make use of MH resources, because it was necessary to the service to be accredited and the current legislation did not allow accreditation exclusively for pediatric cardiovascular surgery. The resources were addressed to the Messejana Hospital, which could not improve the service, because at that moment, this hospital did not have idle capacity, resulting in returning of such resources to the federal coffers - nearly the entire fund. It was argued that there were two services in Brazil accredited with the same purpose, proving thus that the arguments were not sufficient for an attitude in favor of children.

Literal words of the Secretary of State for Health: “If you can change the ordinance, it will be my great pleasure to accredit the service.”

THE NATIONAL DIMENSIONS OF THE STRUGGLE

At the time, it was realized that the problem was not just local, but it had national dimensions and a discuss on the establishment of a national policy to meet - equally - the child and adolescent cardiac patients would be
necessary. At the time, only two services performed exclusively pediatric cardiovascular surgery in Brazil: Pequeno Príncipe Hospital - Paraná, and Instituto Materno Infantil - IMIP, in Pernambuco.

Through BSCVS was scheduled a meeting in the Secretary of Health Assistance, in order to show the need for preparation of an ordinance to meet such demand. There was awareness of the problem, however there was not intention to solve it. At the end of November 2002, the information was received on the need to prepare standards for publication - even during the José Serra administration - of the ordinance that specifically would meet children and adolescent cardiac patients. It is not difficult to understand that, due to the short time and the late attitude of the MH, the ordinance would not be published. The President Luiz Inácio Lula da Silva took office in January and Dr. Humberto Costa was named Minister of Health. The discussion returned to the MH. The proposal of the director of the Secretary of Health Assistance was that a detailed study of all Brazilian states would be necessary in order to make possible an establishment of a national policy. The document was prepared and delivered to the MH in the first half of 2003 and the summary was published by the Brazilian Journal of Cardiovascular Surgery in 2004 [2].

THE CREATION OF THE PEDIATRIC CARDIOVASCULAR SURGERY DEPARTMENT

For the discussion with the MH, was needed a specific institution to advocate for the interests of pediatric cardiovascular surgery, which at the time were done by the President of the BSCVS of that time, Jarbas Jakson Dinkhuysen, and the Chairman of the North-Eastern Society of Cardiovascular Surgery , Valdester Cavalcante Pinto Júnior. During a meeting of the board of BSCVS, on 03 April 2003, during the 30th National Congress of Cardiac Surgery, in Goiânia, was requested the creation of the DCCVPed, and such request was unanimously accepted. On April 4, 2003 during the General Assembly of the BSCVS in Goiânia, after exposure of the reasons for the establishment of the Pediatric Cardiovascular Surgery Department, the list of members that would be statutorily required was handed. It was then scheduled the establishment of the Department for the next meeting of the BSCVS, which would occur in the next Congress of Cardiology of the Brazilian Society of Cardiology (BSC). On September 29, 2003, during the Extraordinary Assembly of the BSCVS, that took place at the 58th Brazilian Congress of Cardiology, in Salvador, Bahia, was founded officially the DCCVPed of the BSCVS, after approval of its statutes.

The first board was composed and approved by the physicians Valdester Cavalcante Pinto Júnior (chairman), Marcelo Biscegliatene (secretary), Fábio Said Sallum (treasurer) and Ulisses Alexandre Croti (scientific director).

At the time there was already lack of satisfaction about the creation of DCCVPed, based on the argument that such creation would weaken the BSCVC and complicate the professional exercise of some cardiovascular surgeons. Certainly, these conflicts would be exacerbated during the preparation of the ministerial ordinance.

Throughout this period, the DCCVPed depended financially on donations from industry to sporadic meetings of the direction, or the support from its own directors.

FORMULATION OF A NATIONAL POLICY OF HIGH-COMPLEXITY CARDIOVASCULAR CARE

From January 2003, the MH came to discuss a broad change to the high-complexity care and promoted intensive discussion to prepare a National Policy of High-Complexity Cardiovascular Care. On the roundtable, societies of various specialties - as BSCVS, Brazilian Society of Cardiology, Brazilian Society of Radiology, Brazilian Society of Interventional Cardiology, Brazilian Society of Vascular Surgery, Brazilian Society of Arrhythmia, Artificial Heart Stimulation Department of the BSCVS - DECA and the DCCVPed of the BSCVS – fought for locus of medical action, space for action of hospital institutions and incorporation of products traded by societies - by their own interests and/or industries. On the other hand, the MH attempts to center – in an university hospital network - the high-cost care and reduce the number of publicly-funded private hospitals by preparing a highly exclusionary policy due to the numerous requirements for hospital institutions with respect to physical structure, equipments and human resources, without appropriate financial counterpart.

The BSCVC, throughout the process, signaled for developing a policy that may meet regional differences and for the fact that it was impossible to meet all the requirements proposed by MH, since most of the services registered in cardiovascular surgery was going through serious financial deficits.

The pediatric cardiovascular surgery passed through difficult times during the negotiation. First, because MH wanted to establish the pediatric cardiovascular surgery as a high-cost procedure and thus to be performed only in university or educational hospitals, which would reduce drastically the number of procedures in the country, because most of this network hospital was damaged. The attempt was to centralize in the public sector such actions. The evidence that the investment per procedure in 2002 (hospital, professionals and industry) in pediatric cardiovascular surgery totaled about RS 6,894.40 [2], that
some devices used in procedures to other specialties reached seven times this value, and that the network established in the public sector was not sufficient to meet the demand, allowed us to overcome this obstacle. On the other hand, segments of BSCVS and DECA understood that the policy discussed at the time contradicted professional interests and hospitals, which would not act in its fullness, or that is, without performing all procedures authorized until then. Then, they started to work by lobbying members of the Legislative and Councils such as the CONASEMS (National Council of Municipal Health Secretaries) and CONASS (National Council of Health Secretaries), to hinder the ordinance in its entirety.

In a meeting requested by members of BSCVC in São Paulo, at the MH, in the presence of the Minister of Health, the DCCVPed was excluded from the appointment, because they considered that its presence could complicate negotiations. On the eve, the President of BSCVC of the time, Dr. Jarbas Jakson Dinkhuysen, warned about the intent on the meeting, that was to prevent the finishing of the ordinance. However, the DCCVPed participated and obtained from the Minister, Dr. Humberto Costa, the maintenance of the ordinance that favored the pediatric cardiovascular surgery. In that same time, it would be achieved a reduction of requirements for cardiovascular surgery services.

During the last meeting with MH technics, before the approval of the text, the last attempt to exclude the norms related to Pediatrics has occurred, by occurring even the question by the director of the Secretary of State for Health, as follows: “So, is it to exclude Pediatrics?.”

The legal landmark occurred on June 15, 2004, by the Ordinance N° 1169/GM, that established the National Policy of High-Complexity Cardiovascular Care [6], and by the Ordinance N° 210 SAS/MS, on the same date, that regulated the pediatric cardiovascular surgery [7].

THE CHILD WITH HEART DISEASE AND HIS RECOGNITION AS A SUBJECT OF RIGHTS

What is being a child? How do they think, feel and live? Cohn [8] in 2005, warns on need to understand the child and his world based on his point of view. Thus, the author states categorically: “If we really want to answer those questions, we need to free from preconceived images and approach this universe and this reality by attempting to understand what is in them, but not what we expect them may offer us.”

The word childhood is recorded in the dictionaries as the period of growth that is from birth to entry into puberty, around 12 years of age. According the Convention on the Rights of the Child, adopted by the UN General Assembly in November 1989 [9], “children are all persons under eighteen years of age.” For the Statute of the Child and Adolescent (ECA) (1990) [10], child is considered a person until the twelve years of age, while the adolescence is considered between twelve and eighteen - age of civil majority (18 years old).

Etymologically, the word childhood comes from the Latin, infantia, and refers to the individual who is not able to speak. This inability, attributed to early childhood, extends until the seventh year, which represents the age of reason. It is realized, however, that chronological age is not sufficient to characterize childhood. This is what Khulmann [11] in 1998, emphasized categorically: childhood has a generic meaning, and as any other stage of life, this meaning is result of social changes. Every society has its system of age classes and a system of status and role is associated to each of them.

Philippe Ariès [12], a famous French historian, notes in 1978 that childhood was an invention of modernity, constituting a social category developed recently in human history. For this author, the emergence of a sense of childhood as an awareness of the infant condition, is based on long historical course, not being a natural heritage. The XVI and XVII centuries outlined a conception of childhood focused on innocence and infant weakness [12]. The eighteenth century opened the establishment of modern childhood, assuming the sign of freedom, autonomy and independence [12].

For Ariès [12], the childhood feeling dates of the nineteenth century. Until then, children were treated as adults in miniature and small adults. The special care they received - when occurring - was reserved only to the first years of life, and to those under a better social and financial condition.

Heywood [13] in 2004, made a severe criticism on the Ariès’s studies. For this author, Ariès was naive in dealing with its historical sources, and too focused in the Middle Ages, and very extreme when emphasizing the absence of childhood in medieval civilization. Heywood [13] shows in his study that there was a childhood in the Middle Ages, even though the society did not have enough time for children. Also, he presents the thesis on which the church has been worried about education of the children who worked at the monastery. According this author, even in the XII century was possible to find evidence of a psychological and social investment on children. In the XVI and XVII centuries, there was “an awareness that perceptions of a child were different from those of adults” [13].

As the childhood, adolescence is currently understood as a historical category, which has significations and meanings, but far from essentiality. As noted by Pitomboira [14]: the naturalization of adolescence and its homogeneity can only be analyzed in light of society itself. Thus, the
“natural” characteristics of adolescence are understandable only when placed in the history that produced them, but the adolescence was not always approached this way.

For most authors of human behavior, to be adolescent is to live a period of physical, cognitive and social changes which, together, favor to delineate the profile of this population. Currently, the adolescence is seen as a stage of human development acting as a bridge between childhood and adulthood. From this perspective of “connection”, adolescence is also seen as a period per passed by crisis, which guides the young towards the conquest of his subjectivity. Adolescence, however, can not be achieved only as a transitional phase. Indeed, it is much more than that [15].

Adolescence, a period of life between puberty and adulticidal, comes from the Latin adolescencia, adolescer. It is commonly associated with puberty, derived from the Latin word pubertas-atis, referring to the set of physiological changes related to sexual maturation, which reflects the gradual transition from childhood to adolescence.

As the same way Ariès emphasized the modern feature of childhood, this author [12] believes that adolescence also emerged under the sign of Modernity, from the twentieth century. As a result, the author affirms: the first typical adolescent was Siegfried, of Wagner. For the first time, the Siegfried’s music expressed a mixture of purity (provisional), physical force, nature, spontaneity and joy of life that would make him the hero of our XX century, the century of adolescence.

Only after the establishment of the sense of childhood in the nineteenth century, it became possible the emergence of adolescence as a phase with peculiar characteristics, distinct from other stages of the human development [12].

The basic condition that favored the “inauguration” of occidental adolescence of the twentieth century was, mainly, the possibility to prescind financial aid from young people who now can devote more time to professional education. Moreover, the contemporary and technical reality requires increasing professional improvement, leading to a lengthen in the period of preparation of young people for entering in the job market. In parallel, it also increases the time of custody of children by their parents, since they stay more time in schools [15].

Although the beginning of recognition of childhood occurred in the XVI and XVII centuries, there was need for legal landmarks, such as the Convention on the Rights of the Child [9], adopted by the UN General Assembly in November 1989 and in Brazil the Statute of the Child and Adolescent [10] in 1990 for the triggering of actions to promote the well-being for this age group. Thirteen years after the publication of the ECA, the MH gives way in its agenda to the child and adolescent with heart disease.

The preparation of the National Policy of Pediatric Cardiovascular Care is a process opened by the personal initiative to solve a repressed demand in the state of Ceará, aiming to care children and adolescents with heart disease. The absence of norms that could incorporate appropriate services to meet the care on Pediatrics - and thus contribute to reducing the waiting lines for surgery - triggered a national movement for the recognition of the sector and establishment of rules that may allow the full exercise of cardiovascular surgery in hospitals that meet the new rules. Here, the establishment of a classical liberal concepts of Adam Smith in his book “An Inquiry into the Nature and Causes of the Wealth of Nations” is noted: It is thus that the private interests and passions of individuals naturally dispose them to turn their stock towards the employments which in ordinary cases are most advantageous to the society (...). Without any intervention of law, therefore, the private interests and passions of men naturally lead them to divide and distribute the stock of every society, among all the different employments carried on in it, as nearly as possible in the proportion which is most agreeable to the interest of the whole society. (Smith apud Morais) [16].

It can be assessed the attitude of managers of the Secretary of Health of Ceará in two phases: in the first, facing the absence of a pediatric cardiovascular surgery service in the State to meet the demands. There was an attempt to exempting from investments, seeking to press the private associated network to increase the frequency of operations, which became disinterested in the maintenance of care in its fullness, due to the values practiced by procedure. With the obligation to invest, there was slow in establishing the project activities, as well as the exclusion of some of its parts. In the second, when given increase in service supply through accreditation of non-profit institution, in order to meet the demand – with awareness on the burden of payment of the procedures to be hired – the responsibility to achieve economically and legally the incorporation of another hospital for the child and adolescent cardiac patients is transferred to the civil society.

Diniz [17] points out that “one of the factors responsible for poor infrastructure afford was the damage of the state’s ability to perform its basic and not transferable functions as a guarantee of order and public safety and to ensure minimum conditions of existence for large parts of the population, located in the poorest regions. Under the impact of fiscal and political crisis, and as a result of the first wave of liberal reforms inspired by the cuts in spending and personnel, it has deepen the historical state’s inability to penetrate throughout the national
The creation of DCCVPed has become visible the pediatric cardiovascular surgery, encouraging more surgeons to enter or return to this area. Possible, too, identity and specificity in discussions within the BSCVS and together with the public authorities, especially the MH.

During the negotiations for preparation of the Ministerial Ordinance of high-complexity cardiovascular care, the MH attempted to center the high-cost procedures in the university hospitals. A strong intervention by the hospitals – that viewed the exclusion of this type of care - that is still profitable – forced the MH to include the educational hospitals in the list of institutions with the right to interfere in this segment. The DCCVPed achieved to demonstrate that the costs of the procedures showed to be unsuited to the concept of high-cost proposed by the MH, enabling all accredited units to work in a thorough manner. Another argument brought to the discussion was the damage of the university hospitals, together with State’s inability to favor the structuring of services that may meet the demand. Polignano [18] confirmed in this article the same situation:

The University Hospitals, the last redoubt of excellence hospital care – at a level of SUS -, also come into crisis. In 1997 the University Hospitals of the country “were forced” to reduce the number of attendances, and induced by the government to be privatized as a solution to solve the financial crisis in the sector. The reason of such crisis was the low price paid for the services rendered by hospitals to the SUS and the delay in releasing these resources. The debts of the university hospitals exceeded the amount of 100 million reais (April, 1997). Many of them worked with half the number of staff needed to operate.

The MH, when publishing the norm for establishment of cardiovascular surgery services and providing resources for the accreditation of new institutions, warns that it wants to get involved in solvation of the demands so far observed in the country. However, throughout the process, issues such as adequacy of values applied to pay hospitals, professionals and industries have been systematically excluded from the agenda of negotiations.

FINAL CONSIDERATIONS

It is emphasized the relevance of civil society participation in the development of social policies and is mandatory - for the further discussion on issues in the social area - the intervention of agents who experience difficulties, either as patients, patients’s family or professionals in the area. The search is for full democratization in preparation of policy and that the agents – non-members from the Government - are not only used to legitimize the desire of the dominant class.

It is understood that non-observation - by the MH - of the regional differences, when publishing standard norms for all and non appropriated remuneration per procedure should impair the expansion in care.

Only with further analysis of the results of the four years of establishment of norms will be possible to define clearly the mistakes and successes of this policy.

REFERENCES


