A debt with our nation's health: the case of congenital heart diseases

Walter J. Gomes[1] and Working Group of BSCVS on National Programme for the Full Treatment of Children Diagnosed With Congenital Heart Disease: Aldemir José da Silva Nogueira, Fabio Biscegli Jatene, José Teles de Mendonça, José Wanderley Neto, Leonardo Andrade Mulinari, Luiz Fernando Caneo, Marcelo Biscegli Jatene, Marcelo Matos Cascudo, Valdester Cavalcante Pinto Junior.

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Accepting the quality of healthcare provided to Brazilians has become untenable, not only to the population as a whole, but especially to patients and their loved ones as well as doctors and other related professionals. The situation becomes worse when it compromises children with congenital heart diseases, stripping them of their basic rights to proper care and the chance of remaining alive.

The article by Pinto Jr. about the difficulties of caring for children with congenital heart diseases, published in this issue of the Brazilian Journal of Cardiovascular Surgery, is particularly timely as it does a great job of showcasing part of the reality faced by all of us in our daily routine [1].

Epidemiological data show a painful reality, in which 65% of the 23000 children diagnosed with congenital heart disease needing surgical treatment born annually in Brazil do not have access to the procedures requested. The largest discrepancies are found in the North and Northeast of the country (93.5% and 77.4%, respectively); the smallest, in the South and Mid-West (46.4% and 57.4%, respectively). These children grow up with the natural progression of the disease. Consequently, they face high mortality rates and restrictions in their quality of life, both preventable considering more than 70% of them could be cured if treated appropriately. Resources dedicated to the treatment of congenital heart diseases are insufficient and, most of the time, are re-allocated to other departments whose productivity results are more visible thereby impressing authorities [2,3].

With a growing concern about this omission, the Brazilian Society of Cardiovascular Surgery (BSCVS) has made every effort to find solutions for this deficit. A group of specialists was gathered to tackle the problem by formulating several proposals for a definitive solution, which were then referred to the Brazilian Society of Cardiology (BSC) to be discussed.

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The joint efforts of the BSCVS, supported by the vigor and enthusiasm of the BSC, represented by its president, Dr. Jadelson Pinheiro de Andrade, along with the Brazilian Society of Hemodynamics and Interventional Cardiology (BSHIC) and the Brazilian Society of Pediatrics (BSP) and its departments, resulted in the creation of a committee formed by specialists from those Societies. The committee developed the National Program for the Full Treatment of Children Diagnosed with Congenital Heart Disease. The goal of the program is to develop an instrument, backed by the Health Ministry as well as other social segments and governmental agencies, to solve once and for all the grim picture of the treatment of children with congenital heart disease in Brazil [4].

Among the proposals presented, the creation of a specialized Secretariat, the Special Secretariat for the Treatment of Children with Congenital Heart Disease (SETRACCC), under the Health Ministry is particularly noteworthy. By receiving resources for managing and fully treating children with congenital heart diseases, the Secretariat administration would make it possible to both channel these resources specifically to these patients and create the Centers for Full Treatment of Children with Congenital Heart Disease (CETICCCs), thus avoiding scattering in the use of these resources. The proposal establishes the allocation of financial resources intended solely for the full treatment of children with congenital heart disease; the expansion of the capability to assist patients as well as improvements to existing centers; the opening of new centers in deprived areas; and training of teams specialized in this type of treatment, to be allocated evenly throughout the country, thereby ensuring patients in need have universal access to this type of treatment.

According to the guidelines set out in the proposal,

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financing will come from specific funding allocation, with funds being released through the special Secretariat, regardless of ordinary funding from the Public Healthcare System.

The Program reiterates and calls for compliance with Article 11 of Statute of the Child and Adolescent: "Child's and adolescent's access to healthcare is guaranteed through the Public Healthcare System, ensuring universal and egalitarian access to actions and services for the promotion, protection, and recovery of health".

The proposal has been delivered and is currently being analyzed by the Health Ministry. Thus, there is an urgent need to raise awareness of the gravity of the problem so that positive and concrete actions can be taken; enabling assistance to these children and reversing the picture of oblivion toward them. The proposal should also be used to set an example to correct the healthcare system in Brazil, making it more fair and efficient.

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