

EDITORIAL

Epidemiological Profile: An Important Step in the Organization of Medical Care

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Editorial referring to the article: Associated Factors with Congenital Heart Disease in the Most Populated State of Brazil Between 2010 and 2018

The demographic-epidemiological study of a disease allows for a more accurate characterization of situations involving the care of this pathology and a better distribution of resources, often scarce, thereby optimizing patient care. In a scenario of general lack of financial, technological, and professional resources, it is necessary to develop a program that addresses all processes, streamlining the care network flow and, consequently, that produces a positive impact on the outcome. Continuous reassessment of methods and criteria are necessary in order to evaluate the need for the reorganization and redirection of resources.

When treating congenital heart disease (CHD), the estimated prevalence may seem insignificant, when compared to other more prevalent cardiac pathologies, such as coronary artery disease. In Brazil, a prevalence of 12:1,000 live births with CHD has been estimated, corresponding to 25,757 new cases per year. These were responsible for 6% of all deaths in children < 1 year of age, according to data from Pinto Jr.,¹ Salim et al.,² observed that the main cause of death in young people under 20 years of age between 2000 and 2015 was circulatory system malformation.² The clinical presentation of diseases is extremely variable, with symptoms that can start from the fetal period to adulthood and the correct diagnosis at an appropriate time is a determining factor for better therapeutic management and success. Lopes et al. demonstrated a lethality of 64.7% for critical CHD, which proved to be higher during the neonatal period.³ However, data on mortality must be interpreted in the context of available medical care in the studied region.

Keywords

Congenital Heart Disease; Epidemiology; Public Health Administration; Risk Factors; Social Class, Maternal Health.

Socioeconomic conditions, genetic backgrounds, and environmental exposures can all affect maternal and fetal health, thus influencing birth rates of CHD.⁴ The study of risk factors related to heart disease is extensive in the literature and some are already known to lead to increased risk, such as maternal diabetes mellitus, the use of non-hormonal anti-inflammatory drugs, increased nuchal translucency, monochorionic twins, among others. In these cases, the diagnostic and prevention processes could be better targeted by analyzing the populations at a higher risk.⁵ Even though it is estimated that only 8% to 12% of CHD can be explained by environmental factors, they still represent a significant burden of disease whose impact could be potentially avoided.

Liu et al.,⁶ in a large meta-analysis, detected a progressive increase in the incidence of CHD in most countries around the world, predominantly of smaller defects (ventricular septal defect, atrial septal defect, and patent ductus arteriosus), most likely reflecting an improved detection through the dissemination of the use of echocardiography.⁶ In a country with continental dimensions, such as Brazil, healthcare programs take on distinct aspects in each macro-region according to the available resources and local health policies. In all regions, however, the lack of diagnosis is a major issue, together with the unavailability of hospital beds, the difficulty to refer patients to specialized centers, and counter-referencing; the high cost of procedures; as well as the lack of qualified multidisciplinary teams and an underreporting of events.⁷ At this point, underreporting, a variable common to other diseases, results in a general misunderstanding of the true CHD scenario, hindering the proper destination of resources. To solve this point, a unified and universal program is required, encompassing the various care levels and a database that can be accessed by all the actors involved.⁸

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The National Center for Cardiovascular Health Specialized in CHD (RENASCE), a project instituted by the Brazilian Ministry of Health since 2017, is a CHD care program that seeks to encompass the entire line of care: prevention and early and accurate diagnosis, through the necessary treatment or interventions and counter-referencing to local healthcare centers. It is a broad, comprehensive, and complex plan in view of the geographic dimensions and disparity in resource distribution in Brazil; however, if properly implemented, it could result in a substantial improvement in the care of these patients, reducing infant mortality, especially for patients under 1 year of age.⁹

In the article "Associated Factors with Congenital Heart Disease in the Most Populated State of Brazil Between 2010 and 2018",¹⁰ the authors investigate, in a mixed-design study, the epidemiology of CHD in the state of São Paulo, Brazil. Data was obtained from the Brazilian Information System on Live Births (SINASC), part of DATASUS, the official online data source from the Brazilian Ministry of Health, which encompasses both the public and private healthcare systems. The cases collected were newborns diagnosed with heart-related cardiac malformations (ICD 10th revision Q20.0 to Q24.9) during the stay in a maternity ward and reported in the Certificate of Live Births (CLB). In this database it is possible to retrieve maternal and newborn epidemiological data. It was observed that, between 2010 and 2018, 9,618 cases of CCD were reported out of 5,496,668 births. Considering that the expected incidence would be 1% (54,966 cases), what could contribute to this underreporting? Most likely, the low rate of prenatal diagnosis plays an important role in this scenario due

to the lack of access to adequate prenatal care, including diagnostic imaging tests.¹¹ The pathophysiological characteristics also determine a later onset of symptoms, which corroborates the need for thorough physical examination associated with screening tests, such as the pulse oximetry test, often unavailable or performed inadequately.¹²

Another interesting data of this important study, which points to the need for improvements in the notification system, was the high percentage of cases classified as cardiac malformations with no specific diagnosis. This was the second type of malformation most described. In an initial reflection, we can question whether the delay in the correct diagnosis could have impaired the patient's insertion in the CHD care network, impacting the final prognosis. The higher rate of specific diagnoses observed in the state capital reflects the greater availability of resources and therapeutic methods. It also demonstrates the concentration of services offered in addition to the probable referral of cases from other states. In a country with such significant distances, the strengthening of regional services, even for "high complexity" pathologies, can be a determining factor in ensuring the appropriate treatment. This comes to emphasize the importance of associating or inserting the classification of the degree of complexity and its effective referencing to the line of care.

Studies, such as this, are necessary for the organization of a care network for a disease with great impact and complexity, helping to develop more effective networks and, consequently, improving results. Periodic reassessment, using a healthcare notification system, enables the improvement of public policies and the distribution of resources.

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