

Editorial



New Suggestion for Congenital Heart Disease Prevalence Studies

Sin Weon Yun , MD, PhD

Department of Pediatrics, Chung-Ang University Hospital, College of Medicine Chung-Ang University, Seoul, Korea



► See the article “Nationwide Birth Prevalence of Crucial Congenital Heart Defects From 2014 to 2018 in Korea” in volume 54 on page 838.

Received: Sep 30, 2024

Accepted: Oct 7, 2024

Published online: Oct 24, 2024

Correspondence to

Sin Weon Yun, MD, PhD

Department of Pediatrics, Chung-Ang University Hospital, College of Medicine Chung-Ang University, 102, Heukseok-ro, Dongjak-gu, Seoul 06973, Korea.
Email: yswmd@cau.ac.kr

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ORCID iDs

Sin Weon Yun 
<https://orcid.org/0000-0001-8947-703X>

Funding

The author received no financial support for the research, authorship, and/or publication of this article.

Conflict of Interest

The author has no financial conflicts of interest.

Data Sharing Statement

The data generated in this study is available from the corresponding author upon reasonable request.

Although the diagnosis rate and treatment outcomes for congenital heart disease (CHDs) have improved significantly in recent years, CHDs remain one of the leading causes of birth defects and neonatal mortality. The overall incidence of CHDs varies among researchers, with reports ranging from as low as 4 per 1,000 to as high as 50 per 1,000.¹⁻⁴⁾ This significant discrepancy can be attributed to several factors. First, many severe CHDs are associated with significant chromosomal abnormalities, which increase the risk of spontaneous abortion or stillbirth, as well as the mortality rate immediately after birth. Consequently, these cases may be overlooked before diagnosis. Second, if all cases that regress spontaneously—such as small ductus arteriosus, foramen ovale,⁵⁾ ventricular septal defects, or mild pulmonary stenosis—are included in the diagnosis, the reported prevalence of minor CHDs may be artificially inflated. Additionally, the prevalence of CHDs can vary significantly depending on the timing of the initial echocardiography. Third, if a patient is initially diagnosed at a facility where CHDs surgery is not feasible and is subsequently transferred to a higher-level hospital where the surgery can be performed, there is a risk of double counting these cases.

The recently published nationwide prevalence study on critical CHDs in South Korea is relatively accurate and highly significant, utilizing extensive medical big data.⁶⁾ However, due to the complex nature of critical CHDs and the limitations inherent in multi-institutional retrospective studies, various factors may introduce inconsistencies. These factors include data omissions or duplications resulting from multiple surgeries, transfers between hospitals, and changes in primary diagnoses. In cases of complex CHDs that require interventional or surgical treatment, relatively accurate data can be obtained. However, for simple CHDs that do not necessitate treatment, achieving accurate prevalence rates is impossible. For these reasons, studies on the precise incidence of CHDs are scarce worldwide,^{1,4,7,8)} and the findings are often limited. Although it may be challenging, including all diagnosed CHDs could help provide a clearer understanding of the true natural prevalence.

Several studies on racial differences in the prevalence of CHDs have reported that Asians exhibit a higher incidence of right-sided obstructive lesions such as tetralogy of Fallot, pulmonary atresia, and critical pulmonary stenosis. In contrast, Western populations show a higher incidence of left-sided obstructive lesions including hypoplastic left heart syndrome, coarctation of the aorta, and aortic stenosis.^{2-4,8-10)} Recent research provides substantial support for these findings by systematically organizing various previous studies.⁶⁾

The contents of the report are the author's own views and do not necessarily reflect the views of the *Korean Circulation Journal*.

Korea's prevalence rate of CHDs is anticipated to change slightly in the future due to several factors, including the world's highest rate of prenatal diagnosis, a significant decline in the birth rate, an increase in artificial reproductive technologies, and a rise in premature births.⁶⁾

South Korea boasts a comprehensive national resident registration system, a robust national health insurance program, and world-class prenatal and pediatric echocardiography services. Furthermore, it is recognized as a global leader in online services. By leveraging these resources, we can collect diverse and accurate data on various CHDs, which will provide a significant advantage.

In addition, to address the limitations of retrospective medical studies that utilize commonly used simple International Classification of Diseases codes within the context of big data, it is essential to develop an accurate input system for complex CHDs. This system should be established under the guidance of specialized institutions, such as the Pediatric Cardiology Society, and should facilitate the creation of a new nationwide CHDs big data input system that encourages participation from all medical professionals.

If the national big data system is effectively utilized to facilitate the automatic and comprehensive entry of each patient's diagnosis, critical medical records, and surgical and interventional treatment history, it will enable a groundbreaking study. This research will not only assess the prevalence of various types of CHDs but also examine their natural progression and treatment outcomes, making it the first of its kind globally.

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