

# ОГЛЯД ЛІТЕРАТУРИ

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## CONGENITAL HEART DEFECTS IN CHILDREN: THE CURRENT STATE OF THE PROBLEM AND CHALLENGES FOR THE HEALTHCARE SYSTEM

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### CONGENITAL HEART DEFECTS IN CHILDREN: THE CURRENT STATE OF THE PROBLEM AND CHALLENGES FOR THE HEALTHCARE SYSTEM

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**Background.** Congenital heart defects (CHDs) are among the most common congenital anomalies worldwide. They adversely affect human health, lead to disability, and remain a leading cause of infant mortality.

**Objective.** To summarize the global prevalence of CHDs among live-born children and worldwide trends in improving diagnosis and treatment. The term “trends” refers to temporal changes in the reported prevalence of CHDs and mortality rates, which depend on healthcare system factors, including screening organization, case registration, and access to treatment.

**Results.** The global prevalence of CHDs ranges from 8 to 12 ‰. Structurally, the most common defects are VSD (40%), ASD (14%), PDA (10%), PS (7.6%), TOF (5.5%), CoA (4.7%), TGA (3.7%), HLHS (2.6%). With timely surgical intervention, up to 95% of affected children survive. In Ukraine, approximately 4.500 children with CHDs are born annually, of whom about 30–40% require surgical treatment during the first year of life.

**Keywords:** congenital heart defects, children, healthcare system, challenges for the healthcare system.

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### ВРОДЖЕНІ ВАДИ СЕРЦЯ У ДІТЕЙ: СУЧАСНИЙ СТАН ПРОБЛЕМИ ТА ВИКЛИКИ ДЛЯ СИСТЕМИ ОХОРОНИ ЗДОРОВ'Я

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**Актуальність.** Однією з найчастіших вроджених аномалій у світі є вроджені вади серця (ВВС), які завдають шкоди здоров'ю людини, призводять до інвалідизації і є основною причиною летальності немовлят.

**Мета** – узагальнення глобальної поширеності ВВС серед живонароджених дітей та тенденцій щодо поліпшення діагностики та лікування у світі. Під «тенденціями» розуміли часові зміни зареєстрованої частоти ВВС та показників смертності, які залежать від системи – організації скринінгу, реєстрації випадків і доступності лікування.

**Результат.** Частота ВВС у світі коливається в межах 8–12‰. За структурою найпоширенішими дефектами є: VSD (40%), ASD (14%), PDA (10%), PS (7,6%), TOF (5,5%), CoA (4,7%), TGA (3,7%), HLHS (2,6%). За умови своєчасної хірургічної допомоги 95% дітей виживають. В Україні щороку народжується близько 4500 дітей із ВВС, з яких приблизно 30–40% потребують хірургічного втручання у перший рік життя.

**Ключові слова:** вроджені вади серця, діти, стан проблеми, виклики системи.

#### Introduction

One of the most important and frequent congenital anomalies in all countries of the world is congenital heart defects (CHD), which not only harms human health and often leads to disability, but is also the leading cause of infant mortality worldwide [3; 9; 13; 18; 34; 53; 56]. According to many authors, CHDs account for 30% of all congenital malformations [4; 16; 25; 29; 54]. The

prevalence of CHDs at the global level, according to N. Salari et al. (2023), varies greatly [46]. In a systematic review and meta-analysis, the authors demonstrated that the incidence of CHDs increased significantly from 1970 to 2017, reaching a maximum in 2010–2017 (9.4 per 1.000 newborns) [3; 18; 29; 57]. At the present stage, the prevalence of CHDs varies from 4 to 50 per 1.000 newborns [3; 13; 30; 51], which, according to the authors, may be due not only to the level of economic development of the country, but also to the statistical capabilities of medicine [12; 23; 30]. A detailed understanding of the global, regional, and national distribution of CHDs is crucial not only for prevention but also for the development

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of medical algorithms for early diagnosis and treatment of this pathology.

According to pediatric healthcare system in many countries, the causes of early neonatal and infant mortality are dominated by life-threatening congenital anomalies: almost 26% of perinatal and neonatal deaths are associated with congenital pathology of the child [3; 12; 21; 32; 40]. CHDs remain the leading cause of infant and neonatal mortality. In addition, heart defects rank first among diseases that lead to early disability. Improvement of diagnostic techniques and increase in the number of ultrasound diagnosticians predicts a further increase in the prevalence of CHDs in children due to the increased visualization capabilities of modern technologies.

Therefore, it remains important to study all aspects of the problem of CHDs in children, including the high incidence of children with prognostically unfavorable forms, the need for surgical treatment at an early age, under conditions of anatomical and morphological immaturity of all organs and systems of the child [10; 18; 26; 45; 55]. Not only the qualification of a specialist, but also the capabilities of modern diagnostic equipment play a decisive role in the timely detection of cardiovascular system (CVS) anomalies, in determining timely surgical or conservative treatment, their prospects and prevention of possible postoperative complications [9; 14; 32; 48].

**The aim of the study** was to summarize the global prevalence of congenital heart disease (CHD) among live-born children and worldwide trends in improving diagnosis and treatment. The term “trends” refers to temporal changes in the reported incidence of CHD and mortality indicators, which depend on system-related factors, including the organization of screening, case registration, and access to treatment.

### Materials and methods

The study was conducted using an analytical review design in the form of a thematic narrative review of scientific publications, with elements of descriptive synthesis of data from international epidemiological studies. The literature search was performed manually in the scientometric databases PubMed, ScienceDirect, and Google Scholar. The primary focus was on sources published between 2021 and 2025; however, to ensure a comprehensive contextual understanding of the problem, key publications from earlier years were also included (official documents, foundational reviews, and studies describing the development of approaches to global epidemiological surveillance and the organization of care). Search queries were structured into several thematic clusters (English and Ukrainian language equivalents):

- epidemiology/burden of CHD: “congenital heart disease”, “congenital heart defects”, “incidence”, “prevalence”, “mortality”, “DALYs”, “global burden”, “trends”, “live births”, “children”;

- organization of care and systemic challenges: “health system”, “access”, “inequity”, “screening”, “prenatal diagnosis”, “pulse oximetry screening”, “registries”, “pediatric cardiac surgery capacity”, “workforce”, “referral”;

- clinical outcomes and patient pathways: “pediatric cardiac surgery outcomes”, “postoperative care”, “ICU”, “low cardiac output”, “complications”.

The review included systematic reviews/meta-analyses, large cohort and registry studies, international guidelines, and publications containing comparable data on the prevalence and outcomes of CHD and/or describing barriers to access to cardiac surgical care. Study selection was conducted in two stages (screening of titles/abstracts and full-text assessment), with a focus on relevance to the article topic and data reproducibility. The final analysis included 58 sources, 34 of which were published between 2021 and 2025. The presented data covered 204 countries and territories; however, these were not primary data collected by the authors but rather synthesized international epidemiological estimates reported in relevant global studies that model indicators for cross-country comparisons. No statistical processing in the form of a meta-analysis was performed; the results were summarized using a narrative synthesis approach with a description of key directions and comparison of data across sources.

### Research results and their discussion

CHDs are structural anomalies of the heart that occur at the stage of embryonic development in the period of 2–8 weeks of pregnancy against the background of hereditary predisposition or under the influence of adverse factors of the external (viruses, toxic substances, radiation) and internal (products of altered metabolism) environment, and can vary in type and severity, affecting the function of the CVS in childhood. CHDs comprise anomalies of the position and morphological structure of the heart and large vessels. A significant number of CHDs form pathological conditions of general and intracardiac hemodynamics that affect vital activity.

There were mentions of CHDs as early as the 17th century and by the end of the 19th century most of the main forms of anomalies were described in the literature. The scientific concept of their genesis was formed in the first third of the 20th century, when the ontogenetic theory of the origin of these anomalies was proposed. Further advances in embryology and modern genetic research have significantly supplemented these ideas, but to this day, most of the issues of the genesis of CHDs remain unexplored. According to the authors of [13; 21; 26; 32; 40], 1.27% (1.3–2.0%) of newborns born to mothers with heart disease have CHD, which is ten times more common than the population average. Risk factors for the birth of a child with CHDs are: maternal age, endocrine disorders in the parents, severe nausea and vomiting in early pregnancy and the threat of pregnancy termination, a history of stillbirths, the existence of other children with congenital malformations, a woman taking endocrine drugs to maintain pregnancy, smoking, alcohol consumption, obesity, diabetes, folic acid deficiency, various viruses and infections such as rubella and chlamydia infection. Current research suggests a combination of genetic, epigenetic, and environmental factors as the causal mechanisms underlying the onset of CHDs [31; 40; 44]. In particular, a number of researchers suggest a connection with the immune system. It has been

proven that children with CHDs have an increased risk of infectious diseases with the development of severe complications [14; 39; 42; 48; 58].

Despite significant improvements in the treatment and survival rates of CHDs, there is still little convincing evidence regarding their specific etiology.

The relevance of CHDs poses challenges both medically and socially: the difficulty of diagnosis in the first weeks and months of a child's life is due to the fact that antenatal diagnosis provides detection of approximately 47% of cases of malformations at birth, and 93% by the age of one year; late detection of the defect contributes to complications before and during treatment; 55% to 70% of such children do not survive to the age of 1 without surgical correction; timely referral of patients with CHDs for surgical correction is vital, as prompt surgical intervention allows for the survival of up to 95% of operated patients.

Importantly, the significance of individual risk factors and the possibilities for their control differ depending on the resource capacity of the health care system and the organization of care. In high-income countries, a larger proportion of CHD cases is detected at the prenatal or early postnatal stage, which shifts the focus of system-level solutions toward the quality of screening, timely patient referral pathways, and long-term follow-up of children who survive after correction. In contrast, low- and middle-income countries more often report late detection, limited access to specialized cardiac surgical care, and fragmented registries, as a result of which even potentially modifiable risks (maternal infections, uncontrolled metabolic conditions, nutritional deficiencies, harmful exposures) do not translate into systematic prevention. In this context, "systemic problems" are manifested not so much by differences in the list of risk factors as by differences in the system's capacity to identify them in a timely manner, mitigate them, and ensure a continuous patient care pathway.

Thus, the structure of health system resource capacity can be outlined as follows:

- high-resource systems: priorities include the quality of prenatal diagnosis, neonatal screening, rapid referral pathways, monitoring of postoperative outcomes, and quality of life;

- resource-limited systems: priorities include basic access to diagnostics, regional referral pathways, concentration of surgical capacity, transport/referral mechanisms, minimum standards of intensive care, and registries;

- a universal component for all systems: registries/monitoring, standardized screening and referral protocols, and workforce training.

#### **Prevalence and structure of CHDs**

According to the latest available sources (as of 2024), the rate and structure of CHDs in countries around the world are as follows [1; 12; 18; 21; 39; 41; 43; 44; 55]. For example, in the United States, according to the Centers for Disease Control and Prevention (CDC), the average incidence of CHDs is approximately 8–10 cases per 1.000 live births, and about 40.000 children with CHDs are born in the United States annually. According to the *Canadian Congenital Heart Alliance* and the *Public Health Agency of Canada*, the country has 9–10 cases of CHDs per 1.000

live births, approximately 4000 new cases annually, and more than 250.000 people with CHDs, including adults and children, live in Canada. In England (UK), the average frequency in Europe is about 7.9 per 1.000 births. The Western European rate is also around 7–9 per 1.000 births, but France has one of the lowest rates in the European Union (next to Portugal at 6.7 per 1.000 births, Qatar, etc.). In Germany, about 6.000 children with CHDs are born every year, which, with 750.000 births per year, is 8 per 1.000 births. As for the incidence of CHDs for Asian countries, the average number is approximately 9.3 per 1.000 live births. According to a recent global survey, the highest prevalence of CHDs among live births was reported in India (19 per 1.000 births). In China, the rate of CHDs is 9.3 per 1.000 births (or about 139.500 cases per 15 million births annually), with prenatal diagnosis (2.45 million pregnancies) accounting for 7.41 per 1.000 births of all cases detected. In Israel, there are no publicly available detailed statistics, but a similar frequency to Western Europe is expected 8–10 per 1.000 births. In Japan, the overall frequency is about 9–10 per 1.000 births. In the African region, there is a great deal of variability due to underdiagnosis, but the available meta-analysis shows the lowest reported rates: approximately 2.3 per 1.000 births, but these data unfortunately indicate underreporting and low diagnosis of CHDs in many African countries [3; 14; 39].

According to various sources in Ukraine, CHDs are detected in 2 to 12 per 1.000 live births [20; 49]. Different presentations indicate a rate of 6.6 per 1.000 births, which corresponds to approximately 38–40 thousand children with CHDs annually, but according to Amosov National Institute of Cardiovascular Surgery: 10 children per 1.000 are born with heart defects (10/1.000). So, in Ukraine, the level of CHDs among live births is comparable to that reported in many countries and the estimate ranges from 6–10 cases per 1.000, which is consistent with European indicators.

Of all the CHDs [12; 28; 31; 44; 55], septal defects are the most commonly diagnosed, accounting for 51% of cases. The most common CHD is the ventricular septal defect (VSD), which can be isolated or part of a complex defect. The nature and degree of hemodynamic disturbances in VSD depend on its size, number and location of defects, duration of the disease, timing of surgical correction, as well as the course and possible complications of the early and long-term postoperative period. Atrial septal defect (ASD) is in second place, which is detected later due to its asymptomatic course at an early age. The third place is occupied by the patent ductus arteriosus (PDA), which closes at birth in about 1/3 of cases. If persistent in preterm infants, a significant PDA can lead to heart failure, exacerbation of pulmonary disease, pulmonary bleeding, renal failure, food intolerance, necrotizing enterocolitis, and even death. Tetralogy of Fallot (TOF) is the fourth most common cyanotic heart defect, requiring a mandatory surgical intervention. It is believed that radical correction of TOF in the newborn period can limit the long-term impact of the load on the right ventricle and reduce the impact of hypoxic syndrome on the function of vital organs and tissues [15]. The fifth place belongs to aortic coarctation

(CoA), which is a narrowing of the aorta that is often associated with Turner syndrome. Violation of the normal development of the aorta forms a local narrowing of the lumen of the aortic arch in the projection of its isthmus up to complete interruption. Pulmonary stenosis (PS), which is often found with other defects or genetic syndromes, is characterized by the presence of obstacles that slow down the overall blood flow in the valve area of the pulmonary trunk. The next life-threatening defect that requires surgical intervention in the first weeks of life is transposition of the great arteries (TGA). The last place is occupied by an extremely severe defect – hypoplasia of the left heart (HLHS), which is treated by staged surgery [2; 6; 14; 26; 35]. A number of other anomalies, such as a single ventricle, Ebstein's anomaly, valve damage in Marfan syndrome or obstruction due to hypertrophic cardiomyopathy, and other anomalies are relatively rare and have a minor impact on the overall incidence of congenital heart disease.

Based on the latest available data, the structured incidence of CHDs in these countries is presented in Table 1.

According to the data presented, simple forms such as VSD and ASD are more common. In North America (USA, Canada), there are general trends in improving prenatal diagnosis and neonatal cardiac surgery, which has led to an increase in survival rates with CHDs, and most children survive to adulthood. More than 50% of severe CHDs cases are detected prenatally, but there is an increasing number of adult patients with CHDs, which creates a need for specialized cardiac centers. The structure of CHDs in France is similar to Western Europe: VSD > ASD > PDA > other. In Germany, the structure reflects the trends in Central Europe: VSD – 31%, ASD, PDA, PS – 7% each defect; CoA – 5–8%, TOF – 5.5%, TGA – 4.5%, HLHS – 3.8%. In China, the structure of prenatal cases is as follows: VSD – 17%, TOF – 9.7%, TGA – 3.8%, HLHS – 2.8%, CoA – 2.7%, PTA – 2.7%. Features of the structure in

Japan: VSD is more frequent (60% of cases); ASD (5%); PS (9.6%); PDA (3.6%). The structure for African countries is not available in the publications. In Ukraine, unfortunately, there are no clear national statistics yet, Table 1 provides data from Amosov National Institute of Cardiovascular Surgery: VSD (40%), ASD (10%), TOF (5%), CoA (5%), HLHS (2.5%).

#### Mortality from CHDs

As for the CHD-related infant mortality, as an indicator of the quality and effectiveness of medical care, in children under 1 year of age, according to the Global Burden of Disease Study (1990–2021), in 2021 it was 132.6 per 100,000 (1.33‰) worldwide, a decrease of 54% compared to 1990. Table 2 shows the data on CHD-related mortality in the main regions of the world [3; 12; 18; 39; 56; 57].

As Table 2 shows, in North America there are approximately 0.61 deaths per 1.000 live births with CHD; in Western Europe (including Germany, England, France) – 0.70‰, and in Europe as a whole, including Ukraine, the rate is 0.68 per 1.000 live births. The mortality rate in East Asia (Japan/High-income Asia Pacific: 0.685‰) is at the same level, in China it is slightly lower (0.514‰). As for the indicators of India (0.403‰) and Africa (0.31‰), the mortality rate is actually higher due to insufficient access to surgery.

So, in highly developed countries (<0.7‰), mortality in children under one year of age with CHDs is significantly lower, which is explained by access to early diagnosis and cardiac surgery; in Eastern Europe and Ukraine (0.68‰), the rate is higher, but still below the global average; in middle-income Asian countries and Africa, mortality is significantly higher due to limited access to treatment. All of the above data relate to mortality from all clinically significant forms of CHDs, including infant mortality, primarily driven by critical CHDs that require intervention in the first months of life [16; 39; 47].

Table 1

Structured frequency of the most common congenital heart disease in countries

Country of the world (2024)	Total proportion of CHD, ‰	VSD, %	ASD, %	PDA, %	TOF, %	CoA, %	PS, %	TGA, %	HLHS, %
North America	8–10	25–30	10–15	19	5–7	5–8	8–10	3–5	2–3
Europe	7.9	31	7	7	5.5	5–8	7	4.5	3.8
Germany	8	31	17	4.3	2.5	3.6	6.1	2.2	1.4
England	7.9	30	25	–	–	–	–	–	–
France	7–9	10	–	–	–	1.7	–	–	–
Ukraine	6–10	40	10	–	5	5	–	–	2.5
Asia	9.3	30	15.4	10.2	4.4	3.6	–	–	–
Saudi Arabia	2.1–10.7	30–40	9–18	–	6	–	6–12	–	–
China	9.3	17	22	13.8	9.7	2.7	2.7	3.8	2.8
India (Kanpur)	19	33	19	14.6	4.6	–	–	–	–
Japan	9–10	60	5	3.6	–	–	9.6	–	–
Africa	2.3	–	–	–	–	–	–	–	–

CHD-related mortality in children under 1 year of age in selected regions and countries

Region/country*	CHD mortality in children < 1 year (per 100.000)	Per ‰ (per 1.000)
North America (high-income)	61.0	0.61
Western Europe (incl. Germany, England, France)	70.0	0.70
Eastern Europe (Ukraine)	68.0	0.68
Japan	68.5	0.685
China (East Asia)	51.4	0.514
India (South Asia)	40.3	0.403
Saudi Arabia/Middle East	56.0	0.56
Central Sub-Saharan Africa	310.0	3.10

\* The indicators are presented according to published sources (reviews/global estimates/reporting materials). The values are aggregated (estimated) and depend on the methodology of the primary sources and the year of estimation; they are not the result of the authors' own calculations based on primary datasets. Additional statistical estimates (SE/95% CI) were not calculated, as the study is of a review nature and does not use primary individual-level data.

However, it should be emphasized that over the past 30 years, the global mortality rate from CHDs among children under 1 year of age has decreased by about 52–56%: from 289.5 to 132.6 cases per 100.000 (1.33‰).

#### Access to CHDs treatment

In this study, “access to CHD treatment” is considered a system-level category that includes the availability of specialized centers and teams, geographic accessibility of services, financial barriers/coverage, and the actual coverage of children with timely care. Due to differences in data sources and reporting formats across countries, the literature most often provides proxy indicators (such as the number of programs/centers, workforce capacity, and estimates of the proportion of children receiving interventions). Therefore, the examples presented below illustrate different components of access rather than constituting a direct comparison of a single unified indicator across countries.

Advances in diagnosis, surgical and medical treatment have contributed to a significant increase in the survival rate of children with CHDs [2; 12; 16; 21; 39; 43; 53]. Every year, the number of open surgeries for CHDs is increasing worldwide; however, despite the introduction of new technologies, complications from cardiac anomalies remain a significant problem, for example: infections, vascular disorders, arrhythmias, reduced exercise tolerance and cardiorespiratory endurance, and many other in these patients can persist for a long time, which complicates the long-term prognosis [7; 10; 19; 27; 36; 50].

In addition, in most cases, CHDs manifest themselves in combination with other congenital malformations, which in practice complicates the clinical picture [33; 41; 49; 55]. About 1/3 of the cases of CHDs are combined with abnormalities of the central nervous system, musculoskeletal system, gastrointestinal tract, genitourinary system, as well as with immunodeficiency states [15; 21; 48; 58].

The availability (Table 3) of pediatric cardiac care varies in different parts of the world [6; 7; 11; 16; 19; 21; 24; 34; 38; 54]. In most countries, there is a shortage of pediatric cardiac surgery services. Approximately 90% of children with CHDs are born in countries where pediatric cardiac surgery is either unavailable or almost unavailable. It is estimated that 80 to 90% of children worldwide do

not receive adequate cardiac care for CHDs. North America (USA and Canada) has more than 40 leading centers, these are Group 1 countries where medical care for all children with CHDs is available through public or insurance funding. Interventions for infants and children in Group 1 countries are available everywhere due to the high level of medical development. Europe is provided with more than 210 pediatric cardiac surgery centers in 35 EU/EFTA countries according to the ECHSA database [21; 23; 37]. Most of these countries belong to Group 1 – accessibility and funding by the public system. Germany is one of the countries in Europe that meets Group 1 standards. In England, there are at least 11 children's centers, including Great Ormond Street, Birmingham, Alder Hey, etc., with excellent access and funding. In France, there are no exact figures for the number of cardiac surgery centers, but as an EU country, the accessibility of medical care for children with CHDs is high, provided by public funding, Group 1. There is a great difference in Asian countries: some countries are Group 2, others are Group 3 or even Group 4. China and India fall into Group 2. In China, there are more than 15 high-level clinics, including Fuwai Hospital (National Cardiovascular Center), but cardiac surgery is available only in large cities. India has only about 150 practicing cardiac surgeons; each year, only less than 5% of newborns with critical CHDs receive timely intervention – Group 2 position with limited access and regional focus. Japan, as a high-income country (Group 1), has several high-class pediatric cardiac centers available to all children; three centers are reported in the literature. In Saudi Arabia, there are enough specialized pediatric cardiac surgery centers (King Faisal et al.), the country is rated as excellent (Group 1), although detailed pediatric-specific data are limited. Most countries in Africa are in Group 3 or even 4, meaning that cardiac surgery is only humanitarian or absent. The level of capacity is heterogeneous: while some countries have well-developed cardiac surgical programs, in a substantial proportion of Sub-Saharan African countries specialized care remains limited or episodic.

In order to promote global capacity to increase the number of pediatric cardiac care centers, support is needed to train and strengthen the system to establish independent pediatric cardiac care centers to provide free screening,

Table 3

**Estimated availability of cardiac surgical programs/centers and level of access to care for children with CHD (based on review sources)**

Region/country	Approximate number of cardiac surgical programs/centers	Level of access (qualitative)	Comment (organization/geography/coverage)
North America (USA, Canada)	~40+	High (group 1)	Broad coverage; network of highly specialized centers
Europe (EU/EFTA)	>210 in 35 countries	High (group 1)	Well-developed network of centers; access usually supported by public/insurance systems
Germany	Dozens	High (group 1)	Centers distributed across regions; high level of specialization
United Kingdom	≥11	High (group 1)	National-level centers; stable funding
France	Several/a dozen (mainly in large cities)	High (group 1)	Urban concentration of centers with high overall accessibility
Ukraine	28 (25 in EU/ECHSA)	Limited (group 3)	“Center-based” model; access is heterogeneous across regions
China	~30 high-level centers/programs	Partial (group 2)	High capacity in megacities; marked territorial inequity in access
India	~14 regional programs/centers	Limited (group 2)	Interventions are unevenly available; coverage of critical CHD remains insufficient
Japan	~3 leading pediatric cardiac centers	High (group 1)	High level of care; organized referral pathways
Saudi Arabia	7	High (group 1)	Government specialized centers; high access in key regions
Turkey	26	Variable	Centers are available, but access and coverage may differ between regions
Sub-Saharan Africa (overall)	Isolated programs; a large share of needs covered by missions	Low (group 3–4)	High regional heterogeneity; shortage of specialized programs
South Africa (example of a higher-capacity country)	Specialized programs available	Higher than the regional average	Highlights the heterogeneity of the African continent

*Note:* A “program/center” refers to a facility performing cardiac surgical interventions in children; the figures presented are aggregated estimates based on published sources/reviews and do not represent a complete registry for all countries.

outpatient and surgical care for children with CHDs [5; 7; 16; 19; 22; 37; 52]. Undoubtedly, many countries offer the possibility of providing free surgeries to treat CHDs [8; 11; 17; 24; 36]. In pursuit of this noble goal, it is time for the world to unite, accept the challenges, and pave the way for a future where every child, regardless of socioeconomic background, can receive the vital care they deserve.

#### **Cardiac surgery service in Ukraine**

In Ukraine, significant positive changes have recently occurred in provision of care for newborns with CHDs [20; 49; 50]. The issues of early diagnosis, optimal management of newborns with CHDs, and timely surgical correction are relevant. Programs are being implemented to improve the quality of prenatal and early neonatal diagnosis of congenital heart disease. Significant progress has been made with the use of prenatal Doppler echocardiography, which allows diagnosing or suspecting a fetal heart disease as early as 12–18 weeks of gestation, and in the group of high-risk pregnant women, CHDs are detected with a frequency of 0.4%. Prenatal echocardiography, as an accurate and safe diagnostic method, significantly affects the possibility and effectiveness of timely treatment for most heart defects, especially critical ones.

In Ukraine, about 4.500 children with CHDs are born every year, of whom approximately 30–40% require surgery

in the first year of life [20; 50]. The best medical care for children with CHDs is provided by centers and hospitals equipped with advanced technology, staffed by exemplary teams of pediatric cardiologists, pediatric cardiac surgeons, skilled nursing staff, and paramedical teams who are deeply committed to meeting the needs of children. The hospitals provide a full range of pediatric cardiac services to families seeking care, including outpatient consultations, echocardiography, radiology, pre-hospital care, surgical or minimally invasive procedures, post-operative care, laboratory testing, medications and other consultation services.

With regard to the availability of specialized care for children with CHDs in our country, the analysis of the main selected parameters and the state of their implementation is presented in Table 4. In this study, the concept of access to specialized care is not considered synonymous with “quality of treatment”, but rather as a set of structural and organizational conditions that ensure timely arrival of the patient at a specialized center and the ability to receive high-cost interventions. Therefore, the components presented below focus not on clinical outcomes but on aspects of access: geographic/logistical, diagnostic, resource-based, and partnership/financial.

Components of access to specialized care for children with CHD in Ukraine

Access component	Indicator	Current status/Comment
Geographic access	Access to neonatal surgery	Uneven across regions; high-level specialized care concentrated in major centers (notably Kyiv)
Logistical access	Transport/referral of neonates with CHD	No state air-medical service; relies on local transport capabilities and inter-facility coordination
Diagnostic access	Prenatal diagnosis (coverage)	Operational; coverage estimated at ~47–60% of cases, with substantial regional variability
Resource-based access	Provision of consumables	Unstable; dependent on budget/procurement; affects the ability to perform high-cost interventions in a timely manner
Partnership/financial mechanisms	Collaboration with international foundations/initiatives	Active (e.g., UWCF, “Heart on the Palm”); used as a tool to expand access and cover resource gaps

*Note:* The table reflects systemic conditions that determine access to care and does not assess “quality of treatment” in terms of clinical outcomes.

The components presented correspond to the structural-organizational level of analysis and help explain the reasons for regional disparities in the timely treatment of CHD.

In total, there are 28 cardiac surgery centers in Ukraine, 6 of which specialize in pediatric patients. Here are the main cardiac surgery centers in Ukraine that provide specialized care for children with CHDs:

1. Amosov National Institute of Cardiovascular Surgery (Kyiv), which is considered one of the leading institutions in Eastern Europe, has a specialized department for newborns and children under 1 year of age and performs more than 2.800 cardiac surgical interventions annually, of which ~700 are for children.

2. The Center for Pediatric Cardiology and Cardiac Surgery (Kyiv) is one of the most active centers, performing up to 2000 operations annually, with its own neonatal unit, intensive care unit, ultrasound, and catheterization laboratory.

3. The Heart Institute of the Ministry of Health of Ukraine (Kyiv) also performs pediatric cardiac surgery.

4. Regional centers: Lviv, Kharkiv, Odesa, Dnipro, Ivano-Frankivsk, Zaporizhzhia, Vinnytsia, Ternopil, and others.

At the present stage, these centers perform basic and specialized types of interventions, including open heart surgery with artificial circulation in newborns with critical CHDs: TGA, TOF, HLHS; palliative interventions (shunts, pulmonary artery banding); catheterization and endovascular methods: closure of defects (ASD, VSD), stenting, balloon dilation; less often hybrid interventions.

With timely diagnosis and surgical rehabilitation, 95% of children live a full life. Mortality after heart surgery in children in leading centers of Ukraine is <3%. The survival rate, timeliness of surgical intervention, and complications are affected by such problems as delayed detection, especially in the regions, insufficient qualifications of medical personnel, and limited modern technical diagnostic facilities.

At the same time, the domestic cardiac surgery industry has gaps that hinder rendering effective medical care for children with CHDs. The system’s challenges include uneven access to qualified care between centers and regions, a lack of specialized neonatal teams and transport, limited procurement of consumables (oxygenators, prostheses,

valves), and low coverage of prenatal ultrasound screening – in many areas, it is not conducted at all. The war has also created challenges in logistics, evacuation of children, and provision of medicines. The identified shortcomings in providing timely care to patients with CHDs can be considered one of the reserves for improving the quality of their treatment.

The development of a full-fledged world-class pediatric cardiac surgery system in Ukraine, albeit with uneven access, is an undoubted achievement and a positive prospect for improving the quality and effectiveness of cardiac rehabilitation for children with CHDs. The specialized centers have modern equipment and surgeons who have been trained in Germany, Poland, and Israel. Telemedicine, consultations with international specialists, and experience exchange have been introduced and are being spread. The potential for development lies in raising the regional level and prenatal screening, and the survival of infants with CHDs largely depends on the complexity of the cardiovascular anomaly, the presence of concomitant extracardiac anomalies, and the patient’s age at the time of congenital pathology detection.

Thus, CHDs in infants under 1 year of age has attracted considerable attention worldwide and remains a significant and rapidly growing global problem in the field of child health. However, it has received insufficient attention in public health research. Although the prevalence of CHDs among infants has not decreased markedly globally, the significant decline in mortality reflects progress in medical interventions, improved access to health care, and increased awareness, which has contributed to better outcomes for infants with CHDs. Technical advances in modern medicine have allowed for increasingly more frequent diagnoses of CHDs, including simple and sometimes asymptomatic diagnoses, which may make these conditions more common. On the other hand, the possibility of prenatal diagnosis has influenced both the prevalence of CHDs and the associated mortality and comorbidities. The focus should be on improving the survival rates and quality of life of affected infants. Further research is needed to remove existing disparities and to develop targeted healthcare strategies to sustain and enhance these positive trends worldwide. A comprehensive approach to CHDs is the foundation of a comprehensive strategy to treat these anomalies by

implementing a multifaceted approach that includes a variety of initiatives aimed at prevention, early detection, treatment, education and research to solve the problem with the prevalence of CHDs. A child's life is more important and valuable than the money invested in saving it. By saving a child, doctors restore humanity and faith in each other. Only the desire and means to save lives make sense.

### Conclusions

1. The prevalence of CHD among live-born children worldwide, based on aggregated data, is 8–12%, with interregional differences largely driven by variability in the quality of screening and case registration.

2. The CHD spectrum is dominated by “simple” left-to-right shunt defects: VSD (40%), ASD (14%), PDA (10%); meanwhile, critical/complex forms (TOF, CoA, TGA, HLHS) account for the main contribution to early mortality and the need for highly specialized care.

3. The main global “trend” in recent decades is a reduction in mortality rather than a decrease in CHD incidence: according to global estimates (GBD), mortality from CHD in children <1 year in 2021 was 132.6 per 100,000, representing an approximate 54% decrease compared with 1990.

4. Inequities in indicators (low values in high-income regions around 0.61–0.70‰ versus much higher values in parts of Sub-Saharan Africa around 3.10‰) primarily reflect systemic barriers: access to screening, referral/transportation, specialized centers, and funding, as well as the quality of statistical reporting.

5. For Ukraine, systemic challenges in timely care remain relevant: approximately 4,500 children with CHD are born each year, of whom 30–40% require intervention within the first year; priorities include increasing coverage with prenatal diagnosis, regional referral pathways and neonatal transport, stable resource provision, and development of a network of specialized care.

6. Therefore, improving CHD outcomes globally is most realistically achieved by strengthening system-level components: standardized prenatal and neonatal screening, functional registries/reporting, referral pathways and transport, concentration of complex interventions in centers with appropriate capacity, workforce training, and financial mechanisms to ensure access. These directions form a practical framework for supporting positive trends in survival and quality of life for children with CHD.

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