

Estimates of the Economic Implications of Congenital Heart Defects: Literature Review

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Summary

Background. Congenital heart defects (CHD) are one of the most common birth defects globally. According to several studies, most common CHD are ventricular septal defect, atrial septal defect, patent ductus arteriosus, pulmonic stenosis and tetralogy of Fallot. With the continuous improvement of diagnosis and treatment, there has been a significant increase in overall survival rate over the last two decades. Therefore, need for more medical interventions, longer hospitalization and lifelong specialized care has also increased. In addition to direct medical costs, there is indirect economic burden due to reduced life expectancy, loss of ability to work, out-of-pocket family expenses.

Conclusions. According to research in other countries, the cost of treating and caring for congenital heart defects accounts for a disproportionate share of healthcare expenses. Lithuania does not yet have data on the direct and indirect economic burden associated with congenital developmental anomalies. Accurate and constantly updated data would make it possible to monitor progress in the treatment, care, and prevention of congenital heart anomalies.

Keywords: congenital anomalies, congenital heart disease, economic burden.

INTRODUCTION

Congenital anomalies, also known as birth defects, are conditions of prenatal origin that occur as a single defect or as a group of multiple defects [1]. According to World Health Organization (WHO), approximately 6% of newborns worldwide are born with congenital anomalies that cause lifelong consequences and increase death rates [2]. Based on EUROCAT (European Surveillance of Congenital Anomalies) report, congenital heart defects (CHD) are the most common non-chromosomal anomalies in Europe, with a prevalence of 70.90 per 100.000 live births [3]. Four major subtypes of CHD are ventricular septal defect (VSD), atrial septal de-

fect (ASD), patent ductus arteriosus (PDA) and tetralogy of Fallot (TOF) [4, 5]. Continuous improvement in the healthcare system led to better treatment options for patients with CHD and prolonged their lifespan. Over the last decades, the survival of infants with CHD has significantly improved [6]. It is estimated that in economically developed countries about 90–95% of those born with CHD survive into adulthood [7, 8]. While progress in medicine improves survival, it also comes with an increase in financial burden. Since cardiac defects account for about one-third of all congenital anomalies, it is essential to study the related financial impact on the healthcare system and patients' families.

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CAUSES AND RISK FACTORS

Different approaches distinguish the possible causes and risk factors of congenital heart disease. Genetic abnormalities such as chromosomal aberrations or single gene defects cause about 30% of CHD [9]. Common genetic syndromes related to CHD and other anomalies are Down syndrome, Turner syndrome, Noonan syndrome, 22q11 deletion syndrome and Williams syndrome. Furthermore, environmental factors, such as pollution, maternal infections, or exposure to various toxins, can disturb cardiac development [10]. Socioeconomic factors also play an important role in intra-uterine fetal development. Social deprivation, poverty and reduced access to nutritious food are factors directly related to the increased prevalence of congenital anomalies [11]. It is noted that maternal obesity and diabetes mellitus (CD) are significant risk factors for CHD [12]. However, the majority of causes remain unknown, and further studies are needed to understand possible risk factors for CHD [13, 14].

PREVENTION

Although it is not possible to prevent every case of congenital heart disorder, primary prevention is essential to reduce the probability of the birth defect to occur. One of the most important steps is to maintain a good mother's health as well as limit the known risk factors. Adequate nutrition and dietary intake of vitamins and minerals must be ensured for a mother. Harmful substances, such as alcohol or tobacco, and hazardous substances, including heavy metals or pesticides, should be avoided. It is also important to ensure adequate screening for infections and vaccination [10, 15].

TREATMENT AND CARE

Medical treatment for CHD depends on the severity of the defect. Simple

defects can be treated surgically or may not need interventions, whereas complex cases require long-term support services, including physical therapy and psychological therapy for the patient and the family [16]. Surgical procedures of CHD treatment are not only complex, but also pose a risk of infections and thus prolonged hospitalization time [17]. The most common surgical procedures for CHD are VSD, ASD repair, aortic valvotomy and arterial switch. Depending on the patient's symptoms (NYHA class), it is crucial to evaluate the limitations and consequences while managing these conditions [18]. Moreover, several studies suggested a link between socioeconomic factors and the success of management of the congenital anomalies in infants that should be discussed [19].

ECONOMIC IMPLICATIONS

Continuous improvement in the healthcare system opens new treatment possibilities leading to prolonged patient's lifespan, causing increased financial burden at the same time. Different countries report diverse numbers of costs associated with patients diagnosed with congenital anomalies due to various reasons. It is difficult to evaluate the total cost of CHD because direct medical costs and indirect costs need to be considered. Currently, only a few studies are based on a meta-analysis of the estimated cost of CHD treatment. We singled out and compared the experiences of different studies in treating the most common anomalies – congenital heart defects (Table). The mentioned studies review the average expenses of treatment based on hospitalization costs. Although costs vary significantly due to differences in study protocols, all agree that expenses related to CHD are disproportionally high.

Pasquali et al. carried out research where the total hospital cost of CHD patients' treatment was evaluated. The four most common heart defects were analysed. It was noted that total hospital costs for ASD, VSD, TOF and ASO treatment varied from

12,500 to 50,000 USD per patient, covering the cost of board, operating room, pharmacy, supply and laboratory expenses [23]. According to Kumar et al., congenital heart defects are among the most common causes of hospital admissions of cardiac diseases that account for the most expensive treatment. It was calculated that the most common cause of hospitalisation among cardiovascular diseases is coronary heart disease – 55% of total cardiology admissions compared to only 7.5% of CHD. However, the cost of treatment for CHD was calculated to be two times higher than for coronary heart disease [24]. A study in Belgium by Willems et al. evaluated the cost of surgical procedures for patients with CHD and discovered that surgical complications caused a significant increase in total charge [25].

Although it is crucial to understand direct costs related to a particular disease, indirect costs affecting individuals and their families with CHD also must be considered. Gerber et al. conducted a study in Germany focusing on indirect costs falling on families with children diagnosed with congenital cardiac defects. Based on questionnaire results, non-medical costs are estimated to be 3000 euros per year on average. This includes transportation, day-care facilities and lost work-related income due to a child's illness [26]. Shaf et al. carried out research where both direct and indirect costs for patients with CHD in Columbia were evaluated. Costs of treatment, medical assistance and rehabilitation were calculated to be 25,836 USD per patient per year. This includes direct hospital and ambulatory expenses. Whereas indirect costs such as transportation accounted for 1300 USD per person annually and out-of-pocket expenses were 2058 USD respectively [27]. This study highlighted the magnitude of indirect costs, reporting that the out-of-pocket expenses often represented more than half of the families' monthly budget. Moreover, 75% of caregivers could not continue working because of child's illness. Several studies suggested that mental health needs also play an important role in

Table. Estimates of the economic implications of congenital heart defects

Study	Design	Country	Patients	Data collection period	Estimated cost of treatment
Simeone et al. [20]	Retrospective	USA	9.071	2006-2011	Total: \$355.5 million Annual: \$59.3 million
Mackie et al. [21]	Retrospective, population-based	Canada	59.917	2004-2014	Annual: \$99.7-\$121.2 million
Arth et al. [22]	Retrospective	USA	148.184	2013	Annual: \$6.1 billion

CHD treatment [28]. Patients with CHD tend to have significantly higher chances of developing anxiety and depression. Furthermore, family members are also at risk of psychological distress [29]. Considering the findings of these studies, psychological counselling forms a part of the financial burden associated with CHD.

DISCUSSION

Direct medical costs related to congenital heart disease account for a disproportionate share of healthcare expenditure. It has become increasingly recognised that the burden of these congenital malformations is not negligible. While advances in medical care largely cause increasing expenses, complications are another reason for

high costs. Therefore, creating specialised treatment centres with an experienced team could lead to significant savings.

So far, there is a lack of data about indirect costs related to CHD. Most research considers only medical costs, and the actual magnitude of the burden is not revealed. It is clear from the studies discussed above that a comprehensive analysis regarding all expenses related to CHD is yet to be done.

Currently, there is no data available in Lithuania regarding the financial burden of CHD. Based on studies from other countries, CHD greatly affects both the patient and the healthcare system. Accurate and constantly updated data would make it possible to monitor progress in the treatment, care, and prevention of congenital heart anomalies. It would

also help better plan healthcare budgeted, focus on more efficient care facilities for the patient and provide financial support for the families.

CONCLUSIONS

Congenital heart anomalies are a diverse group of birth defects that causes lifelong challenges for the patient and the healthcare system. Up-to-date screening, treatment and care facilities are essential to efficiently manage these conditions. However, more studies are needed to evaluate the overall financial burden of CHD across the world focusing on most efficacious treatment and care methods. ♦

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Santrauka

ĮGIMTOS ŠIRDIES YDOS IR JŲ EKONOMINĖ NAŠTA: LITERATŪROS APŽVALGA

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Įvadas. Įgimtos širdies ydos (IŠY) yra vienos dažniausių raidos anomalijų visame pasaulyje. Remiantis tarptautiniais tyrimais, dažniausiai pasitaikančios IŠY yra skilvelių pertvaros defektas, prieširdžių pertvaros defektas, atviras arterinis latakas, plaučių arterijos stenozė ir Fallot tetrada. Nuolat tobulėjant gydymo ir diagnostikos galimybėms, per pastaruosius

du dešimtmečius labai išaugo IŠY turinčių pacientų išgyvenamumas. Tai lėmė padidėjusį medicininių intervencijų, ilgesnės hospitalizacijos ir visą gyvenimą trukančios specializuotos priežiūros poreikį bei didesnes su tuo susijusias gydymo ir paciento priežiūros išlaidas. Be tiesioginių medicininių išlaidų, egzistuoja ir netiesioginė ekonominė našta dėl sumažėjusio dar-

bingumo, papildomų šeimos biudžeto išlaidų.

Apibendrinimas. Remiantis kitose šalyse atliktais tyrimais, įgimtų širdies ydų gydymui ir priežiūrai tenkančios lėšos sudaro neproporcingai didelę sveikatos priežiūros lėšų dalį. Lietuvoje kol kas nėra duomenų apie tiesioginę ir netiesioginę ekonominę naštą, siejamą su įgimtomis širdies ydomis. Tikslūs ir nuolat atnaujinami duomenys leistų stebėti šių raidos anomalijų gydymo, priežiūros ir prevencijos pažangą.

Reikšminiai žodžiai: raidos anomalijos, įgimtos širdies ydos, ekonominė našta.

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