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Chapter

# Management of Congenital Heart Disease in Low-Income Countries: The Challenges and the Way Forward

*Osama Elshazali, Murtada Ibrahim and Abdelmoniem Elseed*

## Abstract

In this article, we will discuss the management of congenital heart disease in low-income and low-middle income countries. First, we will review the epidemiology of congenital heart disease in the low-income and low-middle income countries and compare it to that in the high-income countries; cardiac disease is the commonest cause of death globally. The challenges that are facing the delivery of pediatric cardiac services will be discussed and some solutions will be suggested to improve these services. Pediatric cardiac services face huge economic, financial, social, and health care system delivery challenges. Collaboration between countries and non-governmental and philanthropy organizations is strongly needed to improve delivery of pediatric cardiac services in low-income and low-middle income countries. Planning of pediatric cardiac services in these countries should consider the context of each country or region; some countries managed to transform their pediatric cardiac services to be better.

**Keywords:** congenital heart disease, pediatric, low-income countries, low-middle income countries, management, children

## 1. Introduction

Congenital heart disease (CHD) is the most common among all birth defects, occurring in about nine per 1000 live births globally. Fortunately, most of the CHD lesion are simple lesions, but 25% are critical lesions [1], which need urgent intervention within the first six months of age.

Each year about 1.35 million children are born with CHD; the majority of them are born in low-income countries (LICs). LICs have a higher fertility rate of 4.6 per woman compared to 1.6 per woman in high-income countries (HICs). The birth rate in LICs is 22 per 1000 population compared to 10 per 1000 population in HICs [2]. Each year around 140 million babies are born globally [3]; of these 1.4 million are born with CHD. Ninety percent of those born with CHD are born in a place with inadequate resources for pediatric cardiac care [4].

CHD is one of the main seven causes of death globally and has a significant socio-economic impact on the community [5].

The past 50 years have witnessed massive breakthrough advances in cardiovascular care such as improvements in diagnosis, surgical treatment, catheter interventions, and Intensive care management. Survival of newborns with CHD has improved dramatically in HICs. Unfortunately, however, this is not the case in many low and low –middle-income countries where the burden is the heaviest and rates of death and disability continue to increase [6, 7].

Management of CHD requires significant resources, namely, highly developed infrastructure, equipment and highly skilled professionals who need years of training. This makes cardiovascular care in children very costly, and it needs a long time to be established. HICs have perfected the treatment of CHD over the past 50 years and are now able to provide adequate treatment to their population. LICs are only starting to build a structure to deliver such care. Even in HICs, the management of some complex CHD lesions is challenging, but in LICs the management of even simple lesions can be a challenge [8].

In LICs, 90% of children with CHD do not have access to pediatric cardiac services, even in the same country, there is a disparity in the access to the services between rural and urban, rich and poor. The challenges include poor financial and human resources and lack of infrastructure [9].

There is a huge disparity in pediatric cardiac resources between HICs and LICs, to put this difference into perspective we can compare the number of pediatric cardiac surgeons between HICs and LICs; in HICs, there are 1.67 pediatric cardiac surgeons per million population compared to 0.03 in LICs [10].

Pediatric cardiac services are expensive and need resources and large investments in the infrastructure. There is a positive correlation between the economic status of the country and the access to pediatric cardiac services [10].

The challenges and obstacles leading to suboptimal delivery of cardiac care for children with CHD in LICs, and potential solutions to improve access to cardiac care in LICs must be considered within the context of each country or region and social, economic, political and health care systems [11].

Need for greater awareness of CHD, increased education and training for in-country program clinicians, strategic health care planning at governmental and policy levels, and innovative solution for financing cardiac services in LICs are needed to help improve pediatric cardiac services [12].

As mentioned earlier, CHD is the commonest congenital anomaly, representing 28% of all congenital anomalies [13]. Studies from different parts of the world showed variation in the reported prevalence of CHD, some of the differences are due to the study methodology and setting i.e., hospital-based studies show higher prevalence compared to population studies. The prevalence figure of 8–10 per 1000 which came from HICs is generally taken as the approximate prevalence worldwide [8].

Significant geographical differences in the prevalence of CHD were reported. The lowest reported prevalence was in Africa (1.9 per 1000 live birth), the highest was in Asia (9.3 per 1000 live birth), while the prevalence in Europe was 8.2 per 1000 live birth [7].

The reported prevalence figures of CHD in Africa, especially in low-income countries, is not usually accurate and thought to be an underestimate owing to a paucity of data, poor health care system, difficulty in accessing health care system, poor health infrastructure, limited resources and early mortality [6]. CHD occur worldwide and although the incidence and prevalence may vary according to genetic

and environmental factors there is no reason to think that they are lower in LICs compared to HICs [6].

In Africa, CHD is starting to become a major public health concern as the pediatric population represents 50% of the total population [14, 15] and due to the scarce availability of pediatric cardiac services, the affected population is starting to accumulate. CHD has now surpassed rheumatic heart disease (RHD) as the commonest cause of pediatric heart disease in some parts of Africa; presumably, this is related to increased awareness and better diagnostic facilities [16].

Delayed diagnosis is a major problem in LICs; this is due to low awareness of the families and medical professionals about CHD. In HICs, the diagnosis of CHD is established by 1 week of age in 40–50% of patients and by 1 month in up to 60% [7]. In addition, the fetal diagnosis is not well developed in LICs, with only 1% of cases detected antenatally [17], while in HICs prenatal diagnosis is routinely used to detect most of CHD cases before birth. Screening for CHD is not routinely practiced in LICs [1], this combined with low awareness contributes to late diagnosis. Often, late-stage presentation with complications such as pulmonary hypertension and myocardial dysfunction, few benefits from surgical treatment. Because of delayed diagnosis, lack of skilled personnel and non-availability of treatment facilities, the problem is further exacerbated [11].

## **2. Challenges**

### **2.1 Economic and financial resources**

The world bank classifies countries according to their incomes into four groups; in 2022 there are 27 countries in low-income economy (LICs) with Gross National Income (GNI) per capita of \$1045 or less, 55 countries with Lower Middle-income economy (LMICs) with GNI per capita range of \$1046–\$4095, 55 countries in Upper Middle-income economy (UMICs) with GNI per capita range of \$4096–\$12,695, and 80 countries in high-income economy (HICs) with GNI per capita of \$12,696 or more [18].

The majority of LICs are struggling to meet the basic primary health problems such as vaccination, malnutrition, and infectious diseases, making it very hard to provide tertiary pediatric cardiovascular services [6]. Due to lack of awareness, some policymakers and even medical professionals in LICs consider pediatric cardiac services as a luxury and not an essential service [19].

LICs are struggling to provide the health services investment required for life-saving CHD interventions. A study exploring associations between risk-adjusted CHD surgical mortality from 17 LMICs and global development indices [20] found a statistically significant positive correlation between under-five mortality and surgical mortality rate, and a negative correlation between specialist surgical workforce and CHD mortality: as specialist surgical workforce increases, congenital heart surgery mortality decreases, suggesting that adequate workforce is vital to quality congenital heart surgical capacity [20].

The association between outcome of CHD surgery and GNI per capita is well established; in LMICs, surgical mortality for CHD was found to be higher in countries with lower GNI per capita [21]. In addition, low health care expenditure per capita, poverty, malnutrition, and high under-five mortalities also play a significant role [20].

CHD is the second cause of mortality under 1 year of age, the first being infections [22].

There is a huge difference in mortality of CHD between HICs and LICs; in HICs, the mortality is 3–7% compared to 20% in LICs. Mortality figures from CHD in LICs are likely to be underestimated since access to the health services is difficult and the available data is not reliable most of the time. Most of the available data is from patients in tertiary centres rather than community-based studies [8].

### *2.1.1 Solutions and moving forward*

We recommend that LICs governments should look for innovative ways to finance pediatric cardiac services, using partnership models. Targeting potential partners such as private sector, insurance companies, nonprofit organizations and international organizations [11]. The system should be flexible to finance mainly the needed sectors in the community; this will ensure the funds will go a long way in helping many children.

Economic efficiency could be improved by the following measures:

Comprehensive care through dedicated cardiovascular programs and centres, these centres will have important roles including improving awareness, prevention, treatment, staff training and research. These centres will have a high-volume workload and this is likely to lead to more efficient manpower management and cheaper consumables.

The cost of consumables and drugs may also be reduced by tax breaks and by encouraging the production of some of these items locally [11] or purchasing the items in bulk.

At the cardiac centre level, prioritization of intervention types is crucial in the context of severe resource limitations; palliative, staged and off-pump operations may be more suitable and safer than complex interventions [11]; of course, this will raise an ethical and philosophical dilemma when a decision is reached not to intervene in patients with complex congenital defects such as single ventricle palliation [23].

Many studies from LMICs demonstrated that it is more cost-effective to adopt early screening programs [1, 24], streamlining of referral pathways, maintaining a balanced case mix with focus on correctable lesions and provide cost-effective intensive care management through the implementation of clinical protocols and best practices as well as to minimize the use of expensive drugs or treatment modalities [25, 26].

## **2.2 Health care system challenges**

For a health system to be effective, it has to be staffed by well trained and efficient medical, nursing, allied, and administrative staff. To be sustainable, it requires a robust infrastructure, real leadership, good governance, and continuing education program. In LICs the health system is usually not well planned due to a lack of information and unawareness of the local health needs and priorities. The health care system support usually comes from the government with some input from academic institutions and NGOs [21].

Poorly supported health care delivery systems remain a major problem in LICs, which can lead to poor management of CHDs in LICs. There is a clear disparity between the poor and affluent as well as urban and rural settings. In LICs more than 60% of the population reside in rural setting. In LICs the health services are

struggling to provide support for other services and some of these deficiencies could have an adverse effect on the pediatric cardiac services such as poor antenatal care, poorly controlled diabetes in pregnancy, and congenital rubella syndrome. Since the vaccination program is not well-established congenital rubella is still seen in LICs [8].

For a health care system to be functioning well and delivering good service, it has to be affordable, accessible and the population has to be aware of the services [27]. Unfortunately, the health care delivery system in LICs is struggling with all of these three factors.

The costs are excessive for most families [21]. Affordability is one of the main reasons for delayed interventions and the associated high morbidity and mortality [21]. Most of the LICs are trying to provide pediatric cardiac services in public hospitals either free or for a reduced cost but such hospitals lack funding and resources and are extremely busy and overwhelmed [19, 21].

LICs have very few pediatric cardiac centres [26], and they are always located in the main cities. Patients who live in non-urban setting sometimes have to travel long journeys to access such services. Inaccessible services will lead to late presentation and delayed diagnosis, and both are associated with high morbidity and mortality [21, 27].

Awareness of the parents, allied health workers and the health care professionals in LICs is not adequate about pediatric cardiac disease. Parents in HICs are aware and well informed about pediatric cardiac disease. The robust health system in HICs also has several safety mechanisms in the system to detect and diagnose pediatric cardiac disease early such as fetal diagnosis [24], routine neonatal check post-delivery, oxygen saturation screening [1], routine primary health check, and routine school health screening. Lack of awareness in LICs is one of the most important factors contributing to late presentation, missed and delayed diagnosis [6, 27].

In the poorest parts of Africa and Asia, the pediatric cardiovascular services are limited. Some of the larger cities have facilities for diagnosis and intervention of selected and straightforward conditions in older children but infant and newborn services are limited.

The preoperative phase requires earlier detection. Fetal echocardiography and screening programs are not readily available in LICs which leads to delay diagnosis. One study from Sudan showed the antenatal diagnosis was 1% compared to the figures of 10–15% in the HICs [17].

There are many barriers to accessibility and affordability in the process from diagnosis to management [5]. The waiting list in the cardiac centres in LICs is getting longer because of the increase workload and the inability of the existing centres to cope. The waiting list is especially long for stable patients who tend to be pushed down in the list because of the urgent and sick cases.

Postoperative critical care has witnessed slow but steady progress in the developing programs. Cardiac intensive care remains a bottleneck for the waiting list in LICs due to increased length of stay for patients secondary to increased morbidity. In developing programs, the cardiac intensive care unit (CICU) is usually integrated with the general pediatric ICU [5]. While this is useful in terms of reducing the cost and sharing of financial and human resources, this could create a problem for bed availability as pediatric ICU patients may occupy the cardiac ICU beds affecting the waiting list adversely. The teamwork philosophy approach has had a major positive effect on the outcome of cases [25].

The poor economic and financial situation will have a detrimental effect on attracting and retaining trained cardiac physicians and nursing staff [5]. The team that looks after pediatric cardiac disease consists of surgeons, physicians, nurses

and technicians, all are highly trained and receive specialized training that is lengthy and expensive. The LICs must invest in them so the respective countries can develop and maintain pediatric cardiac services. This staff will require continuing job training and reasonable pay and benefits. Unfortunately, most of the time this does not happen and the staff either start working in the private sector, usually in adult centres or migrate abroad to richer countries leading to a brain drain which is a major problem in the LICs [6, 28].

### *2.2.1 Solutions*

The health care systems in LICs need to be reformed to improve the delivery of primary and secondary health care. Pediatric cardiac services are very specialized that need a health system with robust infrastructure [11].

Antenatal care services providers, pediatricians and primary care providers should have increased awareness of aforementioned health care issues. Programs targeting CHD include, screening programs such as fetal echocardiography, oxygen saturations in the newborn prior to discharge, and neonatal examinations should be established.

Creative solutions to tackle access and geographic barriers to care have been used in countries such as India, Brazil, Vietnam, and Morocco. These in-country programs operate mobile health care units that are staffed with trained cardiac clinicians and equipped with portable electrocardiogram and echocardiogram equipment. These units provide outreach services to non-urban communities increasing accessibility to the services, raise awareness of CHD, provide education to local clinicians, and screen children for structural heart disease [8].

Pediatricians with an interest in cardiology, especially in non-urban areas should be provided with support from pediatric cardiologists such as telemedicine facilities and satellite clinics. These services should be easily accessible to the residents of non-urban areas and could improve the care of the children by providing early diagnosis and referral to specialized centres. The above approach is cost-effective since the training is shorter compared to the pediatric cardiology training.

Human resources are the most valuable asset; there is a great need for healthcare workers to be trained, sustained, and retained in LICs [6, 28].

## **3. Centers of excellence**

Every country should strive to establish their own cardiac centres. These dedicated Centers of Excellence (COE) would provide clinical, educational, training, research, and administrative support to the services and the programs within the country in addition to their role in providing patient care [5].

These COEs would lead the service development and be a centre for data gathering, research and development and may serve as a hub for medical missions [11]. The COEs can also lead and coordinate the partnership with global cardiovascular organizations and forums; such partnership can help enormously in establishing cardiac services for children in LICs [9].

If appropriately organized, COEs are economically and financially efficient and can save resources especially if their patient volume is large [5].

The cost of these centres may be shared with the adult cardiology programs to save the resources. The COEs would provide the greatly needed training. They also provide

a hub for visiting humanitarian missions [29] which may promote high standards of practice and training.

COEs may have a major role in education and training of the local teams while visiting teams will train the pediatric cardiac personnel including surgeons, physicians, anesthetists, Intensivists, perfusionists, and nurses. For sustaining the skills, the local team's training may have to be augmented by training abroad. However, training abroad is expensive, and the trainee may not get good hands-on training. Recently, there is a move toward long-term embedding projects, where experienced cardiologists and/or surgeons spend one to 12 months in host programs. This has great value both medically and financially [30, 31].

#### **4. Voluntary and humanitarian initiatives**

Voluntary organizations' partnerships with the local governments can help bridge the gap in pediatric cardiac services [29, 31]. The long-term strategy should be a building of capacity and empowerment of the local team [6]. The twinning program model between local centres and visiting centres is a successful one to follow [26, 31].

#### **5. Research and Development**

There is currently no reliable data on epidemiology and pattern of pediatric cardiac disease in LICs; such information would improve the awareness and help in planning and prioritizing the pediatric cardiac services [8, 32].

#### **6. Conclusion**

Pediatric cardiac services are a burden and a challenge to LICs. Currently, the services available in most LICs are not accessible, not affordable and there is still a lack of awareness about the need for quality pediatric cardiac services. Health planners should be aware that pediatric cardiac services are essential services and not a luxury.

Collaboration and partnerships between international organizations, national and local governments, non-governmental organizations, and patient and family advocates are needed to ensure that children around the world have access to quality and sustainable pediatric cardiac care.

There are some shining examples of countries that managed to transform pediatric cardiac services with strategic planning and leadership, for example, Cuba, India and China.

Capacity building toward the ultimate goal of self-sufficient LIC and LMIC programs will require a paradigm shift in the recognition by the leadership, greater collaboration among stakeholders, encouragement of data sharing, and research development.

#### **Conflict of interest**

The authors declare no conflict of interest.



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### **Author details**

Osama Elshazali<sup>1\*</sup>, Murtada Ibrahim<sup>2</sup> and Abdelmoniem Elseed<sup>1</sup>


1 Department of Paediatrics and Child Health, University of Khartoum, Sudan

2 Department of Paediatric Cardiac Surgery, Ahmed Gasim Cardiac Centre, Khartoum, Sudan

\*Address all correspondence to: o.elshazali@uofk.edu

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