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Congenital Heart Defects in the Health Care System across the World

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ABSTRACT

The incidence of CHDs has been increasing worldwide. Despite the increased knowledge of CHD and advancement in the provided care, CHD is still associated with a high mortality rate in infants. The advancement in the care of patients with CHD has been associated with higher healthcare costs. Caring for children with CHD requires collaborative efforts of multiple clinical specialties. Acquiring and retaining this specialized team of health professionals can be challenging efforts for the administration of any healthcare organization. In the United States, heart centers are distributed over the majority of the states, while it is limited to the reginal centers in Europe only. There are many advantages and disadvantages to centralizing the care for these patients. In order to centralize the care of these patients, major organizational and administrative changes have to be applied. Despite the improvement in the care of CHD in the western countries, the majority of patients with CHD in the low- and middle-income countries receive suboptimal care with below average outcomes. we explore the care for CHD across the world and discover the current challenges.

Abbreviations: CHD: Congenital Heart Defects; CDC: Centers for Disease Control and Prevention; STS: Society of Thoracic Surgery; ECHSA: European Congenital Heart Surgeons Association

Introduction

Congenital heart defects (CHD) are a group of heart structural abnormalities that can present immediately after birth or later on through adulthood. They can vary from a simple hole in the heart to a complete disorganization of the heart structures which could impact the blood flow through the affected person's body. The incidence of CHDs has been increasing in the United States (US), about 1% of births per year are born with a heart defect [1]. One out of four of these births will require heart surgery or intervention within the first year of life [2]. Due to the advancement in the care of patients with CHD, there is an increasing population of adults with CHD. This rate has been growing over the past several decades and surpasses the current number of living infants and children with CHD. Based on the US census data from 2010, the estimated population of people with CHD was thought to be 1.4 million adults and 1 million children [1,2].

Persistent Challenges to the Cardiac Care

Despite the increased knowledge of CHD and advancement in the provided care, CHD is still associated with a high mortality rate in infants [3]. In the recent era, the mortality of infants and children with CHD has been declining, but the need for multi-levels of health care services has been urged by parents, providers and health organizations. Patients with CHD usually have other clinical, developmental and behavioral disabilities or impairments [4]. According to the centers for disease control and prevention (CDC), children with CHD are more likely to require special healthcare services at some point in their lives. Almost two-thirds of children with CHD will need behavioral services, physical and speech therapy, medications and special healthcare [5].

The advancement in the care of patients with CHD has been associated with higher healthcare costs. Better outcomes and

higher survival rates contributed to a larger patient population with multiple other comorbidities. The cost of in-patient health care for pediatric patients with CHD was around $6 billion in 2009 [6]. There are other medical costs like medication, out-patient visits, and procedures that have not been accounted for but should be. Caring for a child with CHD comes with other expenses and financial burdens on the families. These unaccounted-for out of pocket costs include loss of employment or working hours, caregiver expenses in addition to the cost of traveling to the local or regional heart centers for physician visits and procedures [7]. These unaccounted-for expenses can add to the emotional and mental stress that families go through.

Heart Center Components

Caring for children with CHD requires collaborative efforts of multiple clinical specialties. A pediatric cardiologist will be the primary caregiver who places the patient into the tract of observation versus intervention. Cardiac anesthesiologists are needed for surgery or catheterization preparation and cardiovascular surgeons with the surgical team to perform the required surgical procedure. A critical care specialist takes care of the patients in the recovery time after surgery in a critical care setting which requires high levels of critical care equipment and highly trained nurses and respiratory therapists. Acquiring and retaining this specialized team of health professionals can be challenging efforts for the administration of any healthcare organization.

CHD Across the US

Congenital heart centers are distributed all around the US with the majority of states have one or more heart centers, while the minority do not have any program leaving their residents to seek the necessary medical care in one of the nearby states. According to the society of thoracic surgery (STS) public reporting, there are ninety-three centers in the US that report their surgical outcomes to the STS [8]. The majority of these centers are under the big umbrella of a children's hospital or a university-affiliated hospital. A small number of these centers are free-standing centers with separated administration. Better outcomes of these reporting heart centers are directly correlated to their patient volume (cities and states with larger populations) and the number of surgical procedures performed [9,10]. These centers are well equipped with both advanced technology and highly skilled staff, and due to the long-standing history of care excellence, it is easier to recruit and retain staffs well as expanding their existing services. Sweden centralized the medical care that is provided for patients with CHD to only two centers. This provided two regional centers with larger patients load and consequently better survival rate and outcomes [11]. Many other states in Europe have been making the same adjustment and centralizing the care provided to patients with CHD. There are many other advantages and disadvantages of centralizing CHD medical care. In the US, we are far away from being centralized anytime in the near future.

The Natural History of Cardiac Care in Europe

It is known that heart centers with a large annual volume of operations have a lower rate of short- and long-term mortality and better quality of care indices [9]. However, there is currently not any published evidence to date, to guide centers as to what is the minimal number of CHD surgical cases per year that would lead to unsafe and harmful patient outcomes. Aiming for the best outcomes, health care administrations in many western countries have tried to maximize the number of patients with CHD per center by limiting care to a number of qualified centers. In the 1980s, the talk about centralizing the care for patients with CHD was started by a group of cardiothoracic surgeons in Sweden [11]. Initially, the thought was to transition to a functional concentration of services with each center to be specialized in a specific type of complicated heart operation. This idea was challenged by the majority of the heart centers in Sweden at that time due to the related financial strains. Later on, in 1986, the idea of concentrating the heart surgeries to one center was initially promoted, however limiting the care to two centers versus only one center was more desired and then adopted as that can create competition and creativity between these two centers.

Centralized Care Advantages and Disadvantages

The main advantage of centralizing the care in the Swedish experience was improving the survival of patients with CHD. This was associated with significant improvement in care quality. Treating a larger volume of patients with CHD in these two centers generated stronger interest in the field of cardiology and cardiothoracic surgery among the staff and ensured that their clinical expertise continued to grow [11]. Furthermore, some of the patients with CHD that had palliative surgeries performed at one of the prior centers had to be re-operated on with corrective surgeries at one of the two new centers which ultimately improved their survival chances. These advantages were associated with many challenges. The first of these was an obvious need to have better resources in order to provide the care for the patients in these regional centers. The referral system in the small counties that care for these patients had to be changed.

The culture of refereeing the patient to the county's hospital only had to be replaced with a referral system based on the patient's need. This shift also caused the pediatric services in the local pediatric hospitals to change their referral patterns to the regional hospitals and arrange for specific transport services. Major organizational and administrative changes had to be applied, the formation of surgical and medical teams dedicated to CHD was a very important initial step in improving the care of these patients. The pediatric cardiology services in the two regional centers had

to expand and deal with all aspects of pediatric cardiology. The establishment of educational and training programs for physicians and nurses in the regional centers had benefited the trainees in these two centers. However, trainees in the prior centers lacked knowledge and training in pediatric cardiology. Another disadvantage of centralization was the travel time of patients and their families. In order to minimize the burdens of travel, the regional centers started outreach clinic for these patients in the local counties where physicians from the regional centers come in regularly to see these patients for follow up.

The Optimal Heart Center

In the early years of the twenty-first century, there was a general consensus among the European cardiothoracic surgeons based on their individual experience that centralization may improve the outcomes of patients with CHD. Therefore, the CHD committee of the European Association for Cardio-Thoracic Surgery (EACTS) recommended that the optimal structure of the heart center should perform two hundred and fifty operations per year in order to provide a high level of care and to improve the cost-efficiency of the congenital heart centers [12,13]. This professional view of the optimal congenital heart center was approved by the European Congenital Heart Surgeons Association (ECHSA). The suggested structure was to be applied in the majority of European countries and was based on the similarities of the patient's need. However, these countries have a different style of health care management which required administrative changes. The mission statement of this policy was "designing the optimal structure of the heart center which delivers standardized care, provide education for surgical and medical trainees, and establish thriving innovative research in the field of CHD" [13].

Theoretical Centralization of Cardiac Care in the US

If the European model of centralization was applied in the US, there could be an improvement in outcomes as regional centers will have a larger volume of cases which is directly associated with better outcomes based on prior studies [9]. However, due to the large geographic area and population distribution of the US, patients have to travel for much longer distances than patients in Europe. The burden of travel and work leave on family, financial burden and childcare cost may be overwhelming and intolerable [7]. The current small and medium-sized children's hospitals and services which train pediatricians and pediatric cardiologist will lose an important training component or training programs entirely, which could create an unintended shortage of pediatricians and pediatric cardiologists. In the current model, heart centers usually provide a big part of the total children's hospital revenue [14]. Children's hospitals use this revenue not only to support the heart center but the other pediatric services in general. Regionalization could have a negative financial impact on children's hospitals and could lead to a loss of other important pediatric services that serve the local small communities due to loss of funds. Centralization should also be associated with the development of robust transport services, outreach pediatric cardiology clinics, highly supportive social services, and an advanced telemedicine system [15,16]. Insurance reimbursement has to adapt to the centralization by providing coverage for the patients even if they get transferred out of the state in order to receive care in the regional centers.

Applying the European experience in the US may sound like a promising theory. However, it needs changes to the management at the individual, organization, state and federal levels in order to be applied. In the Swedish experience, it took 20 years to centralize the care of four heart centers into two regional centers. Centralization in the US would take a very long time as there are over 90 centers distributed over approximately 40 states. On the other hand, the functional concentration of certain services related to the care of CHD is a more realistic goal over the near future, for example pediatric heart transplantation service could be regionalized. Thus far, we have reviewed the CHD in health care systems in high-income countries, Europe and the US. The care of CHD in low- and medium-income countries is more challenging as it takes place in limited resource environments [17].

Cardiac Care in the Low- and Middle- Income Countries

Care for patients with CHD is widely available in North America and Europe. However, care for these patients in the low- and middle-income countries (LMIC) is either absent or insufficient to cover the local and regional needs [18]. Despite the improvement in the care of CHD in western countries, approximately 90% of children in the world who are born with CHD receive suboptimal care in the best-case scenario. The vast majority of these patients reside in LMIC [19]. The most recent estimation of the mortality rate of patients with CHD in the LMIC showed that 25% of these patients die without receiving treatment through the first year of their life [20].

Challenges of the Cardiac Care in the Low- and Middle-Income Countries

Since the 1940s when the first congenital heart surgeries were performed at only two centers in the US, pediatric cardiac surgery has witnessed a rapid development due to thriving research. This research has expanded knowledge and experience, advanced technology and helped with the enormous federal, state and legislative support of this medical specialty. There has been growing awareness about CHD and its related successes and challenges among the western population and the healthcare community. After a half-century of being practiced widely in the western countries, the pediatric cardiac surgery failed to be transmitted to the LMIC like other advanced medical specialties.

There are several important factors that delayed the advancement and improvement of care for patients with CHD in the LMIC. In LMIC even the government- supported pediatric services are not able to provide the financial support of the high cost of the equipment used during the cardiovascular surgeries. Due to the persistent innovation in the bioengineering field, the cardiopulmonary bypass equipment has been under continuous update which resulted in only a limited number of centers that can perform these surgeries. These centers served as training institutions for the cardiovascular surgeons, cardiologists, intensivists and cardiac nurses. The limited number of training centers caused an extreme shortage of staff that can take care of patients with CHD. The rapid growth of populations in the LMIC has added other challenges to the care of patients with CHD. The highest rate of population growth currently is in Africa which is mostly composed of LMIC [21]. The healthcare spending is very limited in the LMIC and it does not match the gross domestic product (GDP) which restricts the health care services to the necessary services only. Based on the World Health Organization data in 2013, high-income countries spend around 10-15% of their GDP on health care, whereas this spending is restricted to less than 6% in the LMIC [22].

Cardiac Care in the LMIC

In the socialist countries like China, treatment for CHD is free and available for patients who live in the major cities; however, the outcomes have been suboptimal. Patients in rural areas are neglected by the government and they rely on community and charity support to cover the cost of their care [23]. In India, public hospitals provide subsidized treatments for CHD, however, due to the high volume of patients, there has been long waiting time for surgeries to happen, which has been contributing to the mortality and morbidity of these patients due to the urgent nature of the disease [24]. In the majority of African countries, cardiovascular surgery is not available for patients with CHD due to the priority of other non-cardiac diseases such as the contagious epidemic illnesses. The limited financial support and healthcare spending are important disadvantages for healthcare generally on the African continent [25]. In Mexico and the countries in South America, patients with CHD are serviced at the major public and university-based hospitals. Lack of resources and advanced technology added to the long waiting list have been impacting the outcomes of the cardiovascular surgeries in these countries [26]. Liu et al. reported a huge gap in the care provided for patients with CHD between the urban and rural areas in the LMIC. To lessen that gap, mobile cardiac units have been created to survey the children in the rural area. These units are composed of specialized clinicians and equipment such as Electrocardiogram and Echocardiography. Once a patient is identified, a means of transport to the large urban heart center is initiated [23].

The Role of Humanitarian Campaigns

Over the last two decades, many humanitarian campaigns supported by the non-governmental organization (NGO) took place in the LMIC. These campaigns provided medical and surgical treatments for patients with CHD besides the educational and training aspects that involved the local physicians and nurses. The majority of these organizations are founded in Europe and the US [27]. Recently, there have been enormous efforts to transition these campaigns from being a short-term solution to a longer and sustainable one. These efforts led to the pairing of the heart programs in the LMIC with the NGO or major heart centers in the US. The partnership would provide training, education and infrastructure support so the local heart program will be capable of providing optimal care even after the campaigns are ended [28,29].

In the twenty-first century, the priority of the heart centers across the US and Europe has shifted from improving patient's survival to minimizing the morbidity that is associated with CHD. On the other hand, providing optimal care for patients with CHD in the LMIC is still the primary goal for the local cardiac services. In 2006, a group of surgeons and cardiologists in the western countries developed the world society for pediatric and congenital heart surgery (WSCHS) with the vision that every child who is born with CHD anywhere in the world must receive the standard surgical and medical care that is needed regardless of the economic resources of the country. In order for this vision to be achieved, collaborative efforts from the western countries should support the regional heart centers in the LMIC so they become the centers of excellence which could be the referral centers for the nearby countries. Due to the enormous financial and logistic needs, these efforts should be fortified by the international organizations such as the United Nations and the WHO.

Conclusion

We explored the CHD in health care systems across the world. The current efforts in Europe and North America aim to optimize the care and achieve the best outcomes for patients with CHD. Although centralization of care has been achievable and effective in Europe, centralization remains the center of discussion among the American experts in the field of pediatric cardiovascular surgery. In the US, CHD care is taking place in many centers that are distributed across the nation. Centralization is not visible at the current time due to multiple reasons, of which the wide distributed demographics of the US plays a major role. The focus in the low- and middle-income countries across South America, Africa, and Asia is to ensure that patients with CHD receive the care they need as the majority of patients in these countries are receiving suboptimal care in the best-case and being denied the care in many cases. The responsibility of helping the LMIC achieve their goal should be

supported by international governmental and non- governmental organizations.

Conflict of Interest

Support for this project was provided through UAB Department of Pediatric Cardiology funds the authors do not have any conflicts of interest to disclose.

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