# UNIVERSITY OF THE GAMBIA
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**COMMUNITY MEDICINE RESEARCH**

Submitted in Partial Fulfilment of the MB BSc Degree in Medicine and Surgery

## PREVALENCE AND PATTERN OF CONGENITAL HEART DISEASE IN EDWARD FRANCIS SMALL TEACHING HOSPITAL FROM 1ST JANAUARY 2019 TO 31ST DECEMBER 2020

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## DEDICATION

I dedicate this piece of work first and foremost to The Sovereign Lord, by whose grace I am both able to will and able to do.

And to my beloved parents, Mr. Augustine& Mrs. Sukunda .M. Kundeh, who are both taking care of me very well by God's grace.

And to my beloved teachers and lecturers, who have introduce me to the pool of knowledge by God's amazing grace

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# CHAPTER 1

## **1.1 BACKGROUND**:

Congenital Heart Disease is defined as a structural abnormality of the heart and (or) great vessels that is present at birth(1). Anatomic defects range from simple to complex and from trivial to life threatening. It can be broadly classified into cyanotic and acyanotic congenital heart disease(2). Furthermore, a commonly used classification of congenital heart disease is as follows: left-to-right shunt ,right-to-left shunts, lesions without shuts, including obstructive anomalies and vascular anomalies

Congenital heart disease (CHD) is the most common cause of major congenital anomalies representing a major global health problem, and accounts for nearly one-third of all major congenital anomalies worldwide(3). It is the most frequently occurring congenital disorder in newborns and the most frequent cause of infant death from birth defects. Birth prevalence of CHD is estimated to be 8 cases per 1000 live births (range from 3 to 10) worldwide(4)(5).Although the incidence of congenital heart disease (CHD) is similar worldwide, countries with high fertility rates have to bear a greater burden of supporting these patients. In a country with a fertility rate of about eight per woman, the population has to support four times as many children with CHD as in a country with a fertility rate of two(6).

There are additional costs to congenital heart disease other than surgical treatment alone: medical treatment, cost of transport to hospital, which is often difficult in rural Africa and Asia, and loss of parental working time when they have to take the children to a medical Centre/clinic. These costs are disproportionately severe in countries with low incomes per capita, especially sub-Saharan countries (6). Furthermore, Rashid U, Qureshi AU, Hyder SN et al. in their research revealed that multiple factors such as lack of adequately trained health system and socioeconomic constraints were responsible for the delay in diagnosis and management of CHD in developing countries (7).

In The Gambia the situation is even more pathetic as there are no cardiothoracic surgery centers which leaves patients with the options of depending on medical management or overseas treatment which is often difficult to afford. Sadly enough, many patients would have lost their lives or suffer significant complications before getting that golden opportunity

Although congenital heart disease remains an important cause of childhood morbidity and mortality(8), there is limited data on the characterization of the disease in The Gambia. This study is set out to determine the prevalence, clinical and epidemiological characteristics of the congenital heart disease amongst pediatric population at Edward Francis small teaching hospital over a two year period.

## 1.2 SIGNIFICANCE OF THE STUDY

This study is aimed to explore the prevalence of the condition amongst pediatric patients in the Edward Francis Small Teaching Hospital and to determine the commonest congenital heart disease seen in this hospital and the most common form of clinical presentation.

This will provide vital public health information which can be used by the government for policy making, to design protocols and raise awareness about congenital heart disease and in the distribution of resources for essential health care and also provide background data for future researchers to build on in a broader spectrum.

**1.3 RESEARCH PROBLEM**: Owing to the fact that congenital heart disease is a common condition seen in Edward Francis small teaching hospital and there are limited/no data available on it here, it is therefore necessary to conduct a research to know the burden of the disease in our setting.

**1.4 RESEARCH QUESTION**-: It is not uncommon to see patient's with congenital heart disease with delayed diagnosis/being misdiagnosed and manage for other conditions due to limited diagnostic tools in our setting. It is therefore important to know:

What is the prevalence of the condition amongst pediatrics in the Edward Francis Small Teaching Hospital?

Which is the commonest congenital heart disease seen in this hospital?

What is the most common form of presentation?

**1.5 PURPOSE OF THE RESEARCH-:** The purpose of this research is to discover the prevalence of congenital heart disease in Edward Francis small Teaching hospital and to outline the epidemiological and clinical characterization.

**1.6 DELIMITATIONS OF THE STUDY-:** The research shall extend from January 2019-December 2020, and shall include all pediatric age group (0-14yrs) in EFSTH.

**1.7 LIMITATIONS OF THE STUDY-:** Even though Edward Francis Small Teaching hospital is the main referral hospital in the country, the findings may not fully represent

the prevalence within the country. Also since it is a retrospective study employing case series, missing data maybe another challenge in this research process.

## 1.8 OBJECTIVES.

### GENERAL:-

To identify the burden of congenital heart disease in Edward Francis Small Teaching Hospital and to characterize them according to their clinical and epidemiological differences

### SPECIFIC:-

- To assess the prevalence of congenital heart diseases
- To characterize congenital heart disease according to clinical characteristics
- To characterize them according socio-demographic characteristics
- To characterize them according to their clinical presentation
- To characterize them according to the definitive treatment modality required

# CHAPTER 2: LITERATURE REVIEW

## 2.1 DEFINITION

Congenital heart disease also known as congenital heart defect/malformation occur as a result of abnormal embryogenesis of the heart resulting in spectrum of structural abnormalities of heart and great blood vessels which are actually or potentially of functional significance and is usually present at birth(9)(10)(11). And if not managed through appropriate interventions affects quality of life of the individual and potential premature death(8).Generally, conditions that are of no functional significance such as persistent left superior caval vein are excluded from this definition.(11)

## 2.2 EPIDEMIOLOGY

Congenital heart diseases (CHD) are of public health concern worldwide as they contribute significantly to childhood morbidity and mortality (12) (13).This is particularly so in developing countries, especially in sub-Saharan Africa, where non-communicable diseases in the pediatric age group are emerging major health and socioeconomic issues but facilities for early diagnosis and management are often lacking(13). Yet perhaps, it is only part of the problem, with rheumatic heart disease (RHD) remaining the commonest cardiac problem, related to poor socioeconomic conditions (14).

Congenital heart disease (CHD) is the most common congenital malformation diagnosed in newborns(15) and is approximately 30% to 40% of all congenital defects worldwide, occurring either in isolation or as part of other syndromic anomalies(11).Globally, the prevalence of congenital heart diseases among newborns and infants vary between 3 and 14 per 1000 live births(11), with an average of 8 defects per 1000 live births(10)(16) .

Although the estimated incidence of CHD is similar across all countries globally (17), (3)however, CHD data for African countries is sparse and needed(8).Salim G. M. Jivanji, Sulaiman Lubega, Bhupi Reel et al, stated that there is an estimated 500,000 children born in Africa with CHD each year with a major proportion of this in sub-Saharan Africa (18).

In Nigeria, congenital heart diseases are seen in 3.5 out of every 1000 live births(11) and according to a study in a tertiary health facility, Cape Coast teaching hospital Ghana, the overall hospital prevalence of CHD encountered was < 1% of live births, which is consistent with global prevalence of ~ 1% of live births(8)

Ventricular septal defects have been shown globally to be the commonest congenital heart diseases seen in children(12). The reasons for the predominance of VSD are unclear(11). In Ghana, The commonest CHD diagnosed at the facility mentioned above were ventricular septal defects (31.4%) and PDA (5.88%) which is similar to reported cases in Nigeria(8). commonest single cyanotic CHD lesion observed was tetralogy of Fallot (25.5%)(8) which is analogous to other studies conducted within the sub-region and around the world (19),(11).

Furthermore in the same study, 26.58% children diagnosed with CHD were below 1 year old with the majority of those diagnosed falling between the 1–5-year group (50.63%)(8). Gender distribution was approximately the same (1:1) which is the pattern seen globally too (20),(21). isolated CHD accounted for 86.3% which is comparable with other reported proportions in Egypt and India [(22),(23)]. Cyanotic to acyanotic CHD ratio was 1: 1.6 which makes acyanotic CHD the most diagnosed(8), as that has been the trend observed globally.

Since there're no local data on prevalence of congenital heart disease in The Gambia, it will be interesting to see how this compares with the findings of this research.

MORTALITY AND BURDEN OF THE DISEASE

Congenital heart disease caused 261 247 deaths (95% uncertainty interval 216 567–308 159) globally in 2017, a 34·5% decline from 1990, with 180 624 deaths (146 825–214 178) being among infants (aged <1 years). Congenital heart disease mortality rates declined with increasing Socio-demographic Index (SDI); most

deaths occurred in countries in the low and low-middle SDI quintiles of which the Gambia is a part. The prevalence rates of congenital heart disease at birth changed little temporally or by SDI, resulting in 11 998 283 (10 958 658–13 123 888) people living with congenital heart disease globally, an 18·7% increase from 1990 to 2017, and causing a total of 589 479 (287 200–973 359) years lived with disability(24)

The burden of CHD is immense. Advancing technology has improved the outcomes of children with these defects in developed countries. However, the financial impact of a child with CHD has exponentially increased over the last few decades. A recent study found that of the total pediatric hospitalizations in the United States, only 3.6% accounted for treating children with CHD. However, it represented more than 15% of the annual costs for pediatric hospitalizations. As such in sub-Saharan Africa, the cost burden is significant and carries important implications in treating children with CHD.(18)

## 2.3 RISK FACTORS

Factors contributing to birth defects include single gene and chromosomal disorders, environmental teratogens, multifactorial inheritance, and micro-nutrient deficiencies(12). Whilst exposure to medicines and recreational drugs—including alcohol and tobacco—may not greatly contribute to the incidence in low-middle income countries (LMICS) and particularly in sub-Saharan Africa, maternal infectious diseases such as syphilis and rubella greatly increases it(18).Other  factors, such as older age, pregnancy infections, pregnancy-induced hypertension, gestational diabetes, family history of CHD, and lower education level, and several child factors, such as early screening age, lower birth weight and short gestational age, were associated with an increased risk of CHD.(25)

Risk was also found in a population-based cross-sectional survey in Shaanxi province, to higher in twin and multi-fetal infants. It was higher in mothers over

30 years of age than in those under 25 years, and in mothers with ≥3 parity than that in mothers with only one parity.(26)

## 2.4 CLASSIFICATION

Congenital heart defects are classified clinically, as cyanotic and acyanotic [16), according to bluish discoloration of mucous membrane determined by increased level of deoxygenated hemoglobin. (9)

Moreover, *a commonly used classification of congenital heart disease is as follows: left-to-right shunt ,right-to-left shunts, lesions without shuts, including obstructive anomalies and vascular anomalies*

Furthermore, CHD is also classified according to its complexity as: (i) simple defects like: ventricular septal defects, atrial septal defects, pulmonary stenosis, and persistence of ductus arteriosus; (ii) defects with moderate complexity like: Tetralogy of Fallot, aortic stenosis, pulmonary stenosis, and ostium primum atrial septal defect, total anomalous pulmonary venous return (TAPVR),partial anomalous pulmonary venous return (PAPVR) and common atrium; (iii) complex congenital heart disease group which includes: dextro-Transposition of the great arteries (DTGA), double-outlet right ventricle (DORV), tricuspid atresia, pulmonary atresia, congenitally corrected transposition of great arteries, atrioventricular septal defect (AVSD) and truncus arteriosus [4 (10)

Also Congenital heart defects are commonly associated with genetic syndromes including but not limited to Down syndrome, Turner syndrome, 22q11.2 deletion syndrome, 1p36 deletion syndrome and Noonan syndrome. Most often, CHD is sporadic, not associated with a syndrome, and of unknown etiology (6) The most common congenital heart defects are ventricular septal defect (VSD), atrial septal defects (ASD), transposition of greater vessels (TGV), patent ductus arteriosus (PDA), and tetralogy of Fallot (TOF) [2].(9)

## 2.5 CLINICAL PRESENTATION

Clinical presentations and severity of CHDs depend on their types or sub-types. However, most children with CHDs present with failure to thrive, cough, repeated chest infections, difficulty in breathing, exercise intolerance, pallor and bluish

discoloration of mucous membranes (cyanosis) [18].(9) Moreover, Children with CHD, whose diagnosis were missed in early childhood, could be found in schools and may be symptomatic with fast breathing, cough and effort intolerance [11,12]. Others with less critical lesion may be asymptomatic but have a cardiac murmur detected during routine examination [13,14] (13). Children with CHD, especially those with critical lesions, usually present early in neonatal period, infancy and early childhood with increasing severity of their morbid state that often result in early mortality without intervention [2]. Some children with less severe lesions may survive beyond early childhood into adolescence and even adulthood, albeit with increasing morbidity and functional incapacity that result in poor quality of life and psychosocial drain for the affected individuals and also constitute appreciable financial burden on the family and community [2,10].(13)

## 2.6 DIAGNOSTIC MODALITIES

Echocardiography, Cardiac catheterization, Cardiac surgery, or Autopsy where used in the Baltimore Washington infant study(27)

While in a study review done in Nigeria diagnosis made by detailed clinical examination, angiography, necropsy and/or echocardiography were reviewed(11).

In another study India, patients were clinically diagnosed with heart disease and were further evaluated with chest radiography, twelve-lead electrocardiograms, and the confirmation of the diagnosis was done using two-dimensional echocardiography.(28)

## 2.7 TREATMENT

Despite remarkable success in the surgical and medical management of CHD, many interventions are palliative rather than curative, and some survivors still

have significant residual hemodynamic and electrical conduction abnormalities and experience cardiovascular complications over the long term.(29)

The currently available medical, trans-catheter, and surgical methods to treat acyanotic CHD are feasible, safe, and effective.

The currently existing medical, trans-catheter and surgical techniques to manage cyanotic CHD are safe and effective and can be performed at a relatively low risk.

## 2.8 COMPLICATIONS

Growth failure was the most common complication in inpatients followed by congestive cardiac failure, pneumonia, and sub-acute bacterial endocarditis. Sepsis was observed in neonatal age while stroke and meningitis were common in cyanotic CHD. A study done by Harshangi et al. reported growth retardation (56%), congestive cardiac failure (56%), and bronchopneumonia (22%) as complications in their study. Case fatality rate among inpatients in this study was 19.23% and most of the deaths were in neonatal age due to complex CHD, refractory congestive cardiac failure, sepsis, and pneumonia.(28)

# CHAPTER 3: METHODOLOGY

## 3.1 STUDY DESIGN.

A retrospective, observational, cross-sectional study shall be employed in conducting this research. The study population shall include children within the age group of 0-14yrs, diagnosed with CHD in EFSTH, peadiatric unit between 1st January 2019 and 31st December 2020.

## 3.2 SAMPLING METHODS.

The sample is the same as the universe and the sample shall include all the patients diagnosed with congenital heart disease in Edward Francis Small Teaching Hospital, peadiatric unit, between 1st January 2019 and 31st December 2020.

### 3.3 TABLES, VARIABLES AND DIMENSIONS

Table 1: Description of socio-demographical variables of patients to be included in the study at Edward Francis Small Teaching Hospital (EFSTH), January 2021

| Variables | Types | Dimensions |
|---|---|---|
| Age | Quantitative discrete | </=1month<br>>1month-1yr<br>1-5yr<br>6-10yr<br>11-14yr |
| Sex | Qualitative nominal | Male<br>Female |
| Residence | Qualitative nominal | Urban(cities&towns)<br>Rural(villages) |
| Socioeconomic status | Qualitative nominal | Upper<br>Middle<br>Lower |
| Nutritional status | Qualitative nominal | Normal<br>M.A.M<br>S.A.M |
| Consanguinity | Qualitative ordinal | NO<br>1$^{ST}$ Degree<br>2$^{nd}$ degree<br>3$^{rd}$ degree |
| Birth order | Qualitative ordinal | 1$^{st}$<br>2$^{nd}$<br>3$^{rd}$<br>Higher |
| Birth number | Qualitative nominal | Single<br>Twins<br>Multiple |
| Age of mother | Quantitative discrete | <18yr<br>18-24yr<br>25-29yr<br>30yr&above |
| Parity of mother | Qualitative nominal | Prima-para<br>Multipara<br>Grand-multipara |

| | | |
|---|---|---|
| Clinical features | Qualitative nominal | Breathlessness, fever, failure to thrive, congestive heart failure, cyanosis, refusal to feed, convulsions, Clubbing, Pedal edema, Facial dysmorphism, Extracardiac anomalies |

## 3.4 DATA COLLECTION AND ANALYSIS

### DATA COLLECTION

The study will be conducted using patient's records from the paediatrics records office of Edward Francis Small Teaching Hospital. The information needed will be obtained using a structured data collection tool that consist of the patients' socio-demographic and clinical.

### ANALYSIS

Microsoft excel and ASPSS, shall be employed for statistical analysis. The data obtained from patients' folders will be presented to a statistician for analysis and then represented in charts and tables.

## 3.5 ETHICAL CONSIDERATIONS:

Ethical approval for the study will be sought from the Ethical Review Committee of Edward Francis Small Teaching Hospital before it is conducted. Letter of approval will be written to the EFSTH record department in order to be able to access the paediatrics folders needed for data collection. Both parents and patients identities, especially names will not be used during data collection thus maintaining maximum confidentiality throughout the period of the research.

### 3.6. DISSEMINATION PLAN:

The findings of this research will be presented using a power point presentation to a panel comprising of community medicine lecturers and Edward Francis Small Teaching Hospital board. Printed copies will be submitted to the community medicine department, office of the provost and any other relevant authorities. Effort will also be made in order for the study to be published in journal for a wider dissemination.

### 3.7 RESOURCES NEEDED:

The resources needed for conduction of this study includes the following:

- A supervisor
- An Internet facility
- A laptop
- Patient case notes
- Data collection tool to guide the data collection
- Statistician

### 3.8 WORK PLAN:

This table below shows the work plan for the study:

| ACTIVITY | TIME |
|---|---|
| **Literature review** | November-mid December |
| **Proposal writing** | Mid-December-early January |
| **Submission of proposal** | Mid-January |
| **Proposal assessment** | Mid-January |
| **Seek approval; Data collection** | Mid-January-end of February |
| **Completion of data collection; Analysis of collected data** | Early March-end of March |
| **Final report writing** | April |
| **Thesis presentation and evaluation** | May |

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