

Published: June 30, 2023

Citation: Hart JM, Subah OC, et al., 2023. The Prevalence and Pattern of Cardiac Disease Amongst the Pediatric Age Group in Liberia: A Five-Year Retrospective Cohort Study at the John F. Kennedy Medical Center, Medical Research Archives, [online] 11(6). <https://doi.org/10.18103/mra.v11i6.3889>

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DOI
<https://doi.org/10.18103/mra.v11i6.3889>

ISSN: 2375-1924

RESEARCH ARTICLE

The Prevalence and Pattern of Cardiac Disease Amongst the Pediatric Age Group in Liberia: A Five-Year Retrospective Cohort Study at the John F. Kennedy Medical Center

Jonathan Minagogo Hart*¹, **Onyekachi C Subah**², **Eguono Eka-Tally**², **Nyamah B Ballah**², **Varbah A. Sannoh**², **Siafa H. Rogers**², **Foday S. Kanneh**³, **Seth Tally**⁴, **Kemeh Cecelia Flomo**⁵, **Sarah Lamin**³, **Lucynthia B. Nippy-Chea**², **Osiah L. W. Kumeh**³, **Jeneba Jenice Ojukwu**⁵, **Seanan O. V. Subah**⁶

¹ Tikur Anbassa Specialized Hospital

² John F. Kennedy Medical Center

³ University of Liberia

⁴ Jackson F. Doe Memorial Regional Hospital

⁵ United Methodist University

⁶ Bong Mines Hospital

*Correspondence: jmhart206@gmail.com

ABSTRACT

Background: Cardiac disease is a huge public health problem for developing countries. Access to healthcare and diagnostic technologies are known to impact the reported prevalence of heart diseases globally.

Objective: The objective of the research is to determine the number and pattern of heart diseases amongst the pediatric age group in Liberia and set a platform for investment in cardiac surgery.

Methods: We conducted a five-year retrospective study at the John F. Kennedy Medical Center to determine the prevalence of cardiac disease in Liberia. A total of 175 patients were enrolled. Data were analyzed using Excel 2019, Epi Info version 3.5.3 and SPSS V.27

Results: The prevalence of cardiac disease was 7.6 per 1000 live birth. Male to female ratio was 1:1.5. 40.5% of children were diagnosed during toddler and early adolescent while 56.6% were diagnosed during infancy and 2.9% during the neonatal period. Commonest pathologies were ventricular septal defect, acquired heart disease, patent ductus arteriosus and tetralogy of fallot. Diagnosis was made mainly by history and physical evaluation. Easily fatigability, dyspnea and murmur were the commonest sign/symptoms. Down syndrome was the most common associated anomalies. 87.4% of children had no surgical treatment and the status of 72.6% were unknown.

Conclusion: Pediatric cardiac diseases is one of the neglected non-communicable clinical diseases in Liberia with a prevalence of 7.6 per 1000 live birth. An estimated 41,600 children are living with cardiac disease in Liberia with over 87% not having any chance of receiving surgical treatment while a very few are being flown out of the country for treatment. More than 77% of the parents of these children are discouraged from bringing their kids for follow ups as they have grown exhausted from repeated hospital visits without any solution. Also, diagnosis of these conditions is a challenge for doctors in Liberia as many of them have not been trained to make early diagnosis and major diagnosis tools are relatively absent as there is only one cardiothoracic surgeon and one cardiology in the country. Ventricular septal defect, acquired heart disease, patent ductus arteriosus and tetralogy of fallot were among the commonest presenting pediatric cardiac disease.

Keywords: Congenital Heart Disease, VSD, PDA, TOF AHD, Echocardiograph, Surgery, Non-communicable Neglected Tropical Disease

Abbreviations

VSD: Ventricular Septal Defect
ASD: Atrial Septal Defect
PDA: Patent Ductus Arteriosus
TOF: Tetralogy of Fallot
ICU: Intensive Care Unit
ACD: Acquired Heart Disease
RHD: Rheumatic Heart Disease
CHD: Congenital Heart Disease
MR: Mitral Regurgitation
PS: Pulmonary Stenosis
AR: Aortic Stenosis
COA: Coarctation of the Aorta
SPSS V.27:

INTRODUCTION

Background

Pediatric heart disease represents an underestimated heavy burden in developing countries where efforts, including resources, are directed mainly on infectious diseases. In Sub-Saharan Africa, the prevalence of pediatric heart disease is projected to be around 8 per 1000 live births for congenital heart disease (CHD) and at least 1 to 14 per 1000 live births for rheumatic heart disease (RHD).¹

Diseases of the heart in children can be grouped into two major categories: congenital heart diseases and Acquired Heart Diseases (AHD). CHD are further classified into trivial, moderate and severe lesions or acyanotic and cyanotic defects per the pathophysiology and affected heart structure.²

The prevalence of congenital heart disease is estimated at 9.1 per 1000 live births per van der Linde et al. and their increasing incidence in the order of 9.7, 9.9, and 11.1 per 1000 live births at 1 week, 1 month and 1 year respectively.^{3,4} Rheumatic heart disease, which is the commonest type of acquired heart disease remains a major health problem for developing countries such as Oceania, sub-Saharan Africa and South-East Asia.⁵

Management of cardiac disease in sub-Saharan Africa remains a challenge in terms of diagnosis and access to treatment, particularly surgical treatment, thus contributing to an increase in infant mortality and morbidity.⁶ Studies performed in few African countries found prevalence of 5.8% in Cameroon⁷; 1.5% among children in Uganda⁸; 30.4 per 1000 cases in Mozambique⁹; and 6.2% in Bamako, Mali.¹⁰

The effects of the Liberian civil war can be felt in all sectors of the country with the health sector being one of the worst affected that is yet to recover.

There has been no published research work, as per our search of the literature, on the incident and or prevalence of pediatric heart diseases in Liberia. This study intends to investigate the prevalence of pediatric heart diseases and to assess the patterns and distribution among children with cardiac diseases.

Statement of the Problem

Pediatric cardiac disease is one of the neglected non-communicable clinical diseases in the world with a global prevalence of 1 in every 100 live births. As a single entity, researchers have documented with overwhelming evidences that congenital heart disease represents a significant global health burden and continue to be the major cause of mortality amongst infants with congenital birth defects.¹¹

Wubishet Belay and Mukar H. Aiyu, in their review, described Rheumatic heart disease as a complication of untreated throat infection by Group A beta-hemolytic streptococcus with a high prevalence among socioeconomically disadvantaged populations. The reviewers in this review recommend multisectoral collaboration to tackle the burden of RHD by engaging the public, health experts, and policymakers; improving distribution channels for prophylaxis, and increasing research and innovation as critical interventions to save millions of people from preventable morbidity and mortality.¹²

In Liberia, there is no cardiac center to conduct proper cardiac work-up and surgical interventions. Besides, there is only one cardiothoracic surgeon, one cardiologist and two anesthesiologists. Unfortunately, there is no cardiac Intensive Care Unit (ICU) nurses, or perfusionists in the country. Because of these, many children are never diagnosed until their death while those that are diagnosed may never get treatment. Moreover, the chance of having microbiology culture and sensitivity is very low as oftentimes there is the constant lack of reagents coupled with the relative absence of laboratories capable of performing such.

The researchers aim to document the pattern of heart disease amongst this age group and provide a partial outlook into the burden on children and their parents with the expected outcome of instigating a debate into the need for the establishment of a cardiac surgery center in the country.

General Objective

The Overall objective of the research is to investigate and determine the prevalence and pattern of heart diseases amongst the pediatric age group in Liberia.

Specific Objectives

The specific objectives of the research can be summarized in three main domains:

- a) To determine the prevalence of heart diseases amongst children in Liberia;
- b) To determine the methods of diagnosis of cardiac disease in Liberia;
- c) To evaluate the management options available to patients and the rate of referral for treatment abroad.

Significance of the Study

The incidence of heart diseases amongst the children is the same in various countries and different ethnic group with rate of 4 to 10/1000 live births.^{13,14,15} Cardiac diseases amongst children are one of the leading causes of death and the prevalence is rising alarmingly in many developing countries as malnutrition and infectious causes of morbidity and mortality are declining.¹⁴

Our search of the English literature found no documented published research on pediatric cardiac disease and its related subjects from Liberia and as such, there is a knowledge gap in this area of service. The Researchers intend to fill the knowledge gaps created by the lack of these fundamental elements of modern health delivery system and create the awareness to attract urgent investment in the field of cardiac surgery in Liberia.

Scope

The research included all children between the ages of 0 and 15 who were diagnosed with disease of the heart at the nation's highest referral hospital in Liberia, the John F. Kennedy (JFK) Memorial Hospital located in Monrovia, and covers a period of five years beginning 2017 to 2021.

METHODS

Research Designed

The research was designed as a retrospective cohort study of the 'chart review type' investigating all pediatric patients diagnosed of heart disease at the pediatric departments of the major referral hospital in Liberia over a period of five years.

Research Population

The study included all pediatric patients between the age of 0 and 15 years who were registered at

the pediatric department of the John F. Kennedy Memorial Hospital from 2017 to 2021.

Sample Size Determination

The sample size was determined from the sample population, which include all pediatric patients registered, evaluated and diagnosed of heart disease in the facility from 2017 to 2021 and met the inclusion criteria. Our data-collection officers visited the facility in-person. During this time, the registries of patients of the required age range were retrieved, reviewed and the **initials and medical record registration numbers** of patients registered with the diagnosis of heart disease were recorded in a roster.

These **initials, with their medical record registration numbers**, were taken to the medical record where the patients' charts were retrieved, reviewed and data recorded. The total number of patients registered during this period, who met the inclusion criteria as listed below, make up the sample size.

The Inclusion Criteria

- a) Patients between the ages of 0 to 15 years;
- b) Confirmed or suspected diagnosis of heart disease by either echocardiographic evaluation and /or exclusive clinical evaluation;
- c) Must have been registered and has a medical record number and chart with clearly outlined diagnostic evaluation of whatever means.

Exclusion Criteria

- a) Pediatric patient age greater than 15 years;
- b) Patients with medical record registration numbers but charts cannot be found;
- c) Patients with medical record charts but no medical record registration numbers;
- d) Poorly recorded evaluation report that hinders identification of diagnosis;
- e) No indication of the diagnosis of cardiac disease(s) as contained within the chart.

Data Quality Assurance

Data collection forms were generated as per previous studies to meet accepted standards of consistency. Patients' medical records with incomplete information/poorly documented findings were excluded; Indicators entered onto a laptop programed to detect duplicated entry of patients' medical record registration numbers so as to avoid double entry; a second review of all entries were conducted by a second set of investigators to validate the entire process of data collection, verification and entry.

Data Analysis

Data collected was entered and analyzed using Microsoft Excel 2019 and Epi Info version 3.5.3. Statistical analyses were performed using SPSS V.27 program.

RESULT/DISCUSSION

Results

The results are organized in chart forms so as to make navigating easier for our readers.

Table 1: Gender Frequency

| Gender | Frequency | Percentage |
|--------|-----------|------------|
| Male | 70 | 40.0 |
| Female | 105 | 60.0 |
| Total | 175 | 100.0 |

60% (105) of the patients were female while 40% (70) were male.

Table 2: Age Frequency

| Age | Frequency | Percentage |
|------------------|-----------|------------|
| Neonate | 5 | 2.9 |
| Infant | 99 | 56.6 |
| Toddler | 38 | 21.7 |
| Preschool | 17 | 9.7 |
| School age | 9 | 5.1 |
| Early Adolescent | 7 | 4.0 |
| Total | 175 | 100.00 |

The infant population makes up 56.6% (99) of the population; toddler 21.7% (38); preschool 9.7%; (17) school age 5.1% (9); early Adolescent 4% (7) and neonate age group makes up 2.9% (5).

Table 3: Pathology Frequency

| Pathology | Frequency | Percentage |
|---|-----------|------------|
| Ventricular septal defect | 47 | 26.9 |
| Tetralogy of Fallot | 33 | 18.9 |
| Patent Ductus Arteriosus | 33 | 18.9 |
| Acquired Heart Disease | 34 | 19.4 |
| Atrial Septal Defect | 13 | 7.4 |
| Mitral Regurgitation | 4 | 2.3 |
| Pulmonary Stenosis | 2 | 1.1 |
| Aortic Stenosis | 1 | 0.6 |
| Aortic regurgitation | 1 | 0.6 |
| Coarctation of the Aorta | 6 | 3.4 |
| Right ventricular outflow tract obstruction | 1 | 0.6 |
| Total | 175 | 100.0 |

VSD account for 26.9% (47) of the population; CHD 19.4% (34); TOF and PDA make up 18.9% (33) each; ASD 7.4% (13); COA 3.4% (6); MR 2.3% (4); PS 1.1% (2) and: AS, AR and RVOTO 0.6% (1) each.

Table 4: Compound Pathologies

| Pathology | Frequency | Percentage |
|--|-----------|------------|
| ASD, VSD, PDA, AVSD | 5 | 10.9 |
| ASD, VSD, PS | 3 | 6.5 |
| Double outlet right ventricle with subaortic VSD | 3 | 6.5 |
| TOF, PDA | 8 | 17.4 |
| TOF with Stenosis | 2 | 4.3 |
| VSD, AR | 8 | 17.4 |
| VSD, ASD | 6 | 13.0 |
| VSD, PDA | 11 | 23.9 |
| Total | 46 | 100.0 |

46 patients had complex cardiac pathologies: Of these numbers, 23.9% (11) having VSD/PDA; 17.4% (8) with TOF/PDA and VSD/AR each; 13% (6) with VAS/ASD; 10.9% (5) with ASD/VSD/PDA/AVSD; 6.5% (3) with ASD/VSD/PS and DORV with subaortic VSD each and; 4.3% (2) with TOF with stenosis.

Table 5: Signs/Symptoms

| | Frequency | Percentage |
|--------------------|-----------|------------|
| Cyanosis | 20 | 11.4 |
| Dyspnea | 106 | 60.6 |
| Easy fatiguability | 108 | 61.7 |
| Growth Retardation | 15 | 8.6 |
| Murmur | 99 | 56.6 |
| Rheumatic Fever | 20 | 11.4 |

61.7% (108) of patients presented with easily fatiguability; 60.6% (106) with dyspnea; 56.6% (99) with murmur; 11.4% (20) with history of rheumatic fever; 10.9% (19) with cyanosis; and 8.6% (15) with growth retardation.

Table 6: Associated Anomalies

| Anomaly | Frequency | Percentage |
|-----------------------------|-----------|------------|
| Autism | 3 | 11.1 |
| Dextrocardia | 2 | 7.4 |
| Dextrocardia, Down Syndrome | 1 | 3.7 |
| Dominant Right Atrium | 1 | 3.7 |
| Down Syndrome | 15 | 55.6 |
| Single Atrium | 2 | 7.4 |
| Turner Syndrome | 3 | 11.1 |
| Total | 27 | 100.0 |

27 patients had associated anomalies with 55.6% (15) having Down syndrome; 11.1% (3) having Autism and Turner syndrome each while 7.4% (2) had dextrocardiac and single atrium each and 3.7% (1) had dextrocardia with Down syndrome and dominant right atrium.

Table 7: Diagnostic Tools

| Tools | Frequency | Percentage |
|--------------------|-----------|------------|
| Echocardiography | 2 | 1.1 |
| History & Physical | 90 | 51.4 |
| Imaging | 83 | 47.4 |
| Total | 175 | 100.0 |

51.4% (90) of patients had history and physical examinations as diagnostic tools; 47.4% (83) had other imaging modalities and; 1.1% (2) had echocardiography performed (table 7).

Table 8: Treatment Options

| Treatment | Frequency | Percentage |
|-----------|-----------|------------|
| Yes | 22 | 12.6 |
| No | 153 | 87.4 |
| Total | 175 | 100.0 |

87.4% (153) of patients had no surgical intervention while 12.6% (22) of patients were referred (table 8).

Table 9: Outcome

| Outcome | Frequency | Percentage |
|---------|-----------|------------|
| Alive | 43 | 24.6 |
| Dead | 5 | 2.9 |
| Unknown | 127 | 72.6 |
| Total | 175 | 100.0 |

72.6% (127) of patients' outcome are unknown; 24.6% (43) are alive and; 2.9% (5) died (table 9).

Discussion

Researchers have documented, with overwhelming evidences, that congenital heart disease represents a significant global health burden and continue to be the major cause of mortality amongst infants with congenital birth defects.¹¹ We described pediatric congenital heart disease as one of the neglected non-communicable clinical diseases in Liberia as evidence of the fact that over 200 years, children in Liberia have never had the opportunity to be managed for their cardiac pathology as there has never been any permanent cardiothoracic or cardiac surgeon and other cardiac surgery team members to initiate the establishment and conduct of cardiac surgery in the country. Currently, there is only one cardiothoracic surgeon in Liberia which puts the ratio of surgeons to patients at 1:5.2 millions population. In addition, there is near absence of diagnostic tools to help advance accurate and timely diagnosis. As a result of these, it can be safely stated that thousands of children and adults have died of their heart disease without receiving treatment over these periods while many more are living with the burden and consequences of heart disease even in the modern age.

In an effort to begin the process of establishing a cardiac surgery center in Liberia and to get an initial understanding of how common is cardiac disease among the pediatric population, we conducted a five-year retrospective study at the JFK Memorial Center to determine the patten and prevalence of pediatric cardiac disease amongst the Liberian population. A total of 22981 admissions of children ages 0 to 15 years were registered and evaluated at the pediatric department over five years, 2017 to 2021. Of this number a total of 189 patients were diagnosed of cardiac disease. However, only 175 patients met the inclusion criteria while the reminding 14 patients' chats were either missing from the record systems or had incomplete information.

The overall total prevalence of cardiac disease among the pediatric age groups as recorded from our study was 7.6 per 1000 live births. However, the prevalence of congenital heart disease was reported as 6.1 per 1000 live births while that of acquired heart disease (AHD) was 1.5 per 1000 live births. These findings are similar to that which was reported by Dolk H and collogues in a study conducted to determine the prevalence of CHD and its associated mortality in Europe. Data were extracted from the European Surveillance of Congenital Anomalies central database for 29 population-based congenital anomaly registries in 16 European countries covering 3.3 million births

during the period 2000 to 2005. CHD cases comprised live births, fetal deaths from 20 weeks gestation, and terminations of pregnancy for fetal anomaly (TOPFA). The average total prevalence of CHD was 8.0 per 1000 births, and live birth prevalence was 7.2 per 1000 births, varying between countries.¹⁶ Our findings are also closely related to that of a multicenter screening study conducted by Zhao QM et al. In their study, they reported an overall prevalence of CHD of 8.98 per 1000 live births (critical, 1.46; serious, 1.47; significant, 5.00; nonsignificant, 1.07).¹⁷ Also, in a seven-year retrospective review of the registry at Bugando Medical Centre in the Lake Zone of Tanzania conducted by Zuechner A and colleagues, CHD was reported to be the most common occurring heart disease among the pediatric age groups. In this review, a total of 3982 patients received cardiac evaluation including echocardiography studies. 1830 (46.0%) pathologic findings were described. Out of these 1371 (74.9%) patients had CHD, whereas 459 (25.1%) presented with AHD.¹⁸

The male to female ratio was 1:1.5 with a female dominance of 60%. About 40.5% of our children were diagnosed between the toddler and early adolescent while the remaining 56.6% of patients were diagnosed during the infancy period. However, only 2.9% were diagnosed during the neonatal period. These findings concord with that reported by research conducted in African countries. In one study, Zhao QM et al concluded in their multicenter screening study that female predominance was observed for all CHD and mild CHD (significant and nonsignificant) with 7.15 male infants compared to 11.11 female infants.¹⁷ Also, the female dominance in our study has been observed in a seven-year retrospective review of the registry at Bugando Medical Centre in the Lake Zone of Tanzania conducted by Zuechner A and colleagues. This review was conducted between September 2009 and August 2016, at which time a total of 3982 patients received cardiac evaluation including echocardiography studies. 1830 (46.0%) pathologic findings were described with a 53.9% female dominance.¹⁸ Al-Fahham MM and Ali YA in Egypt conducted a study aimed at detecting the distribution of demographic data, perinatal risk factors, types, age, and mode of presentation of CHD among Egyptian children and concluded that the majority of patients was diagnosed within the first year of life (86.7%) and was born to young mothers (91.3%).¹⁹

The most frequently occurring isolated heart pathologies in our study were VSD accounting for 26.9%, AHD making up 19.4%, PDA was 18.9%, ASD with 7.4% and TOF was recorded as 18.9%.

In addition, 40 children had complex pathologies accounting for a total of 26.3% of children. The frequently reported symptoms and physical findings were easily fatigability, dyspnea and murmur in the frequency of 61.7%, 60.6% and 56.6% respectively. Other findings included history of previous treatment for rheumatic fever 11.4%; cyanosis 10.9% and growth retardation 8.6%. The relatively available means of diagnosis in our study were history and physical evaluation as used in 51.4% of patient while 45.5% of patients had other radiographic evaluations. Also, 27 (15.4%) patients in our study had associated anomalies and/or syndrome with Down syndrome accounting for 9.1% of the population and frequently seen in patients with atrioventricular septal defect and TOF. Other associated anomalies were Autism, Turner syndrome and dextrocardia with each accounting for 1.7%. Single atrium was seen in 1.1% of patients with associated anomalies. Unfortunately, echocardiographic evaluation, which is the primary diagnostic tool used in the early diagnosis of children presenting with signs and symptoms of heart disease, was employed in the diagnosing of only 1.1% of our sample size. These results from our study are closely related to findings reported in other studies. In a multicenter screening study conducted in China by Zhao QM et al A, total of 122765 consecutive infants were included. Cases of CHD were identified by echocardiography, clinical assessment, and telephone follow-up. The most common CHD was ventricular septal defect followed by atrial septal defect, patent ductus arteriosus, pulmonary stenosis, tetralogy of Fallot, and transposition of the great arteries. Significantly higher rates of ventricular septal defect and atrioventricular septal defect were found in infants born to mothers aged ≥ 35 years. Extracardiac anomalies were found in 9.3% of CHD cases.¹⁷ In addition, a study conducted in Egypt by Al-Fahham MM and Ali YA also reported findings similar with that contained in our study. According to them, acyanotic CHD was encountered in 79.2%. Isolated ventricular septal defect and tetralogy of Fallot were the most common acyanotic and cyanotic lesions, respectively. Down syndrome (DS) was recorded as the most commonly occurring chromosomal anomaly, and the atrioventricular septal defect was the most characteristic cardiac lesion found among them.¹⁹

Majority of our patients had never had the opportunity to be treated of their disease as it was observed from the study that 87.4% of our sample size had no surgical treatment. However, 12.6% were fortunate to be referred for treatment abroad through the means of philanthropist individuals/organizations. It was also observed that

follow up were low with the current status of 72.6% being unknown as many parents get bored of the repeated hospital visits without any chance of their children receiving permanent treatment while a very few of these patients are having regular follow up. Recorded death among the patients being followed up was 2.9% while it was difficult to estimate the deaths amongst the unfollowed patients as most parents refused to provide information on the status of their children.

Limitation/Challenges

One of the outstanding challenges encountered during the conduct of this research was the accuracy and availability of patients' records. A good number of the patients' records were poorly recorded while other charts could not be found. This research is also limited in its 'single center' design as only one facility, which is in an urban setting, was used. However, these challenges did not influence the credibility and reliability of the data and results of this study considering the fact that the facility involved in this study provides a significant representation of the reality of the burden of pediatric disease in Liberia as the source institution is the only major referrer hospital in the country and as such receives a greater proportion of patients with complex presentations.

CONCLUSION/RECOMMENDATIONS

Conclusion

Pediatric cardiac disease is common amongst the pediatric population and one of the neglected non-communicable clinical diseases in the health sector of Liberia with a single center prevalence of 7.6 per 1000 live births. As per our study, there are an estimated 41,600 children living with cardiac disease in Liberia with over 87% of these children not having any chance of receiving surgical treatment of their disease. The only chance a child may have of being treated for his/her heart condition is for the child to be flown out of the country, which is very expensive and oftentimes parents and their family members are unable to underwrite the cost of such process resulting to death of most of these children without any form of surgical intervention. More than 77% of the parents of these children are discouraged from bringing their kids for follow ups as they have grown exhausted from repeated hospital visits without any solution and as such, these children are left to suffer and die at home. Also, diagnosis of these conditions is a challenge for doctors in Liberia as many of them have not been trained to adequately use the limited diagnostic tools, which are relatively absent at almost all times, to reach a satisfactory diagnosis. Unfortunately, there is only one cardiothoracic

surgeon and one cardiology in the country which greatly limits the diagnosis chances of these children. Ventricular Septal Defect (VSD), Acquired Heart Disease (AHD), Patent Ductus Arteriosus (PDA) and Tetralogy of Fallot (TOF) were among the commonest presenting pediatric cardiac disease.

Recommendations

There is a need to upgrade documentation of maternal information to include events during gestation and childbirth.

There is a need for training of staff in the conduct/management of cardiac disease.

The researchers emphasized the need for urgent intervention to address the burdens of cardiac disease amongst the pediatric population in Liberia.

ETHICAL CONSIDERATION

Institutional Approval

The researchers obtained approval from the Research Ethics Committee of Rescue Children's Heart Foundation and the Institutional Review Board of the JFK Memorial Hospital.

Informed Consent

This study is a retrospective study that involved the use of patients' charts and does not involved interaction with the patients/parents and as such, the used of informed consent was not applicable to data collection process.

Confidentiality

The researchers ensured that the patients' identities and personal details were protected by using

ONLY the Initials and Medical Record Registration Numbers of patients.

Risks Association

Considering that this study does not involve patients'/parents' interaction with the researchers, the risk associated potentials were zero to both the patients and the institutions.

Conflict of Interest

The researchers declared that there is no know conflict of interest as per their knowledge.

Sponsorship

This research work was sponsored exclusively by the Rescue Children's Heart Foundation

ACKNOWLEDGEMENT

We acknowledge the Chairperson and members of the Board of Directors, the Chairperson and members of the Research Ethics Committee and the Executive Committee of Rescue Children's Heart Foundation for providing the fundings and technical supervision to enable us conduct this research. We also recognized the Administration and the record depart of the JFK medical center for allowing us use their facility to conduct this research and for the cooperation provided by the record department.

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