

## Original article

### Prevalence, and factors associated with mortality among children with congenital heart diseases at a tertiary health centre in the Gambia

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## Abstract

**Background:** The burden, morbidities and determinants of mortality associated with congenital heart diseases (CHDs)- an important cardiovascular problem in children, is poorly defined in the Gambia. This study sets out to assess the prevalence, spectrum, treatment outcome, and determinants of mortality in children with CHDs admitted to the main referral hospital in the Gambia..

**Methods:** The medical records of 4336 admitted children aged <15 years were consecutively reviewed over a two-year period. Those with CHDs confirmed with 2-D Echocardiography were further analyzed for socio-demographic and clinical features, including associated complications. The outcomes of hospitalization of the children with CHDs were assessed, and factors associated with mortality were determined using binary logistic regression analysis.

**Results:** CHDs were diagnosed in 111 (2.4%) of the 4336 total admissions during the study period. Ventricular septal defects (29.7%) were the most common CHDs, while tetralogy of Fallot (23.4%) was the most common cyanotic heart lesion. About 20.0% of the children with CHDs had features of Down syndrome. Breathlessness and abnormal heart sounds were the most common clinical manifestations, and pneumonia, failure to thrive/undernutrition were the most common associated complications. In-hospital care mortality was 10.8% and male sex ( $p=0.049$ ), school age ( $p = 0.013$ ), chest pain ( $p = 0.004$ ), pallor ( $p < 0.001$ ) and FTT/undernutrition (0.018) were significantly associated with mortality on bivariate analysis and only pallor at presentation with AOR=14.73; 95% CI 2.35 – 92.37 independently associated with mortality with regression model.

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**Conclusion:** CHDs occur in 24 of 1000 childhood admissions at the only tertiary health facility in the Gambia, and VSD was the most common lesion. One in ten of these children died, and the presence of pallor predicted mortality. Making definitive interventions accessible and affordable for these children will reduce the burden of CHDs.

**Key words:** Congenital heart diseases; mortality; pallor; Determinants

## Introduction

Congenital Heart Diseases (CHDs) are structural abnormalities of the heart and/or great vessels present at birth (1–3). Anatomic defects in the Paediatric heart range from simple to complex lesions and from trivial to life-threatening cardiac defects. (4) CHDs can be broadly classified into cyanotic and acyanotic cardiac lesions and they can also be shunt abnormalities (left-to-right or right-to-left), lesions without shunts including obstructive and vascular anomalies (4-5).

Congenital heart diseases are the most common causes of major congenital anomalies in children and they represent a major global health problem (1-3). They account for about one-third of all major congenital anomalies worldwide occurring either in isolation or as part of other syndromes (1). They are the most frequently occurring congenital disorders in newborns and the most frequent cause of infant death from congenital disabilities (1-3). Birth prevalence of CHDs is estimated to be 8 per 1000 live births (range from 3 to 10) worldwide (1-3). Although CHDs incidence is similar worldwide, there is limited data about CHDs from many countries in sub-Saharan Africa including the Gambia. Jivanji et al, estimated that about 500,000 children are born in

Africa with CHD each year, with a major proportion of this in sub-Saharan Africa. (6). In Nigeria, prevalence of CHDs in hospital-based studies ranged from 1.4 - 9.3 per 1000 live births (7-11) while hospital-based studies from other parts of sub-Saharan Africa reported prevalence ranging from 5 to 40 per 1000 live births. (12-14) CHDs account for over 260 000 deaths globally in 2017 with 90% of these deaths estimated to have occurred in Low- and Middle-Income Countries (LMICs) including the Gambia with little or no facilities to diagnose, evaluate and manage these conditions. (15)

Apart from significant contribution to childhood morbidity and mortality, CHDs also contribute to impoverishment of families with children having these heart defects as direct and indirect costs of caring for children with CHDs are often enormous and beyond the reach of majority of the populace in developing countries. This facilitates the call for governmental and non-governmental supports in care for these children to ensure survival (16-18). Such support may include making facilities for improve screening, prompt diagnosis, treatment, follow-up care and data collection available in developing countries where the burden of CHDs is highest.

Having an audit of the prevalence and burden of the CHDs is an important step in calling attention to this condition in order to facilitate policy changes to ensure early recognition and prompt management of these heart defects. This will ensure survival and improved quality of life for these children and their caregivers. This study therefore set out to determine the prevalence, spectrum, treatment outcome and determinants of mortality in children with CHDs admitted to the main referral hospital in the Gambia- Edward Francis Small Teaching Hospital (EFSTH), Banjul, The Gambia.

## Methods

### Study design and settings

This study was a secondary data-based, cross-sectional study carried out at the EFSTH, Banjul The Gambia. The data of childhood admissions at the hospital between January 2019 to December 2020 were assessed. This was done over a six-month period by the investigators. The EFSTH is the only tertiary hospital in the Gambia. The hospital offers both general and specialist paediatric care to children in the Gambia and receives referrals from all the provinces in the country. The hospital has basic facilities for chest imaging, including chest X-ray and 2-D Echocardiography to adequately diagnose and characterize cardiac defects in children. Babies in the first 28 days of life are managed in the 40-bedded Special Care Baby Unit, while children 29 days to 14 years are managed at the 32-bedded Paediatric ward of

the hospital. The total paediatric (including neonatal) admissions in the hospital per year is about 2500. The Gambia is located on a latitude 13 and 14°N and longitude 13 and 17°W, surrounded by Senegal, in the West African sub-region. The population of the Gambia is about 2.28 million. (19)

**Study period:** This data was collected over a six-month data collection period from January 1, 2019, to December 31, 2020.

### Population

The total number of admissions in children from birth to 14 years during the study period was recorded. Children with CHDs confirmed with echocardiography were noted.

### Sample size and sampling procedure

The estimated sample size was determined using Epi Info(R) sample size calculator. Assuming a prevalence of CHD in children of 2.5% [Khasawneh et al (21)] and a power of 90%, a level of significance at 0.05, and 95% confidence interval, a minimum sample size of 235 was calculated. However, the clinical records of all 4336 eligible children during the study period were consecutively assessed.

### Variables and measurements

The information was extracted from the medical records of the children with CHDs. The main information extracted was age, sex, ethnicity, place of residence (urban or rural), presenting symptoms, essential clinical findings at presentation, nutritional status, and

modalities of management. The nutritional status of the children was assessed by comparing their weight for height (WFH) with the WHO reference weight for height chart (20). Children whose WFH was less than -3SD from the mean on the growth chart were considered severe acute malnutrition, and those whose WFH was less than -2SD were labelled moderate acute malnutrition. For children one month to six months, inadequate weight gain or loss of weight that falls over 2 centiles on their road-to-health chart was considered as a case of failure to thrive (20).

The primary outcome of this study is congenital heart disease diagnosed using 2-D Echocardiography. The secondary outcome was a dichotomized treatment outcome i.e., survived vs. mortality

### **Data analysis**

Data obtained were analysed using SPSS Version 25 (IBM Corp., Armonk, NY, USA). Continuous data were tested for normality and summarized using mean (standard deviation) or median (interquartile range) as appropriate. Categorical variables were summarized using percentages and proportions and the difference between categorical variables was determined using Pearson's chi-square or Fisher's exact as

appropriate. The prevalence of CHDs was determined by dividing the number of children with CHDs by the total number of children admitted during the study period. Binary logistic regression was used to determine factors associated with treatment outcome. Effect size was presented as adjusted odds ratio (OR) with 95% confidence interval, and statistically significant association was reported when  $p < 0.005$ .

### **Results**

A total of 4336 children were admitted during the study period, out of which 111 (2.4%) were diagnosed with congenital heart defects.

### **Socio-demographic characteristics of children diagnosed with congenital heart diseases**

The ages of children diagnosed with congenital heart diseases (CHDs) ranged from one day to 14 years. The majority of children, 98 (88.2%) were under five years of age, while only 11.7% were of school age. Males accounted for 63 (56.8%) of the cases. Mandinka and Fula were the most commonly represented ethnic groups. Approximately two-thirds of the children resided in urban areas, predominantly within the West Coast and Greater Banjul regions.(Table 1).

Table 1: Socio-demographic characteristics of children admitted with congenital heart diseases

Variables	Category	Frequency	Percentage (%)
Age range	Neonates (0-28 days)	6	5.4
	Infants (one to <12 months)	47	42.3
	Under-five (12 to 59 months)	45	40.5
	School age ( $\geq 60$ months)	13	11.8
Sex	Male	63	56.8
	Female	48	43.2
Ethnicity	Mandika	42	37.8
	Fula	28	25.2
	Wollof	15	13.5
	Serahule	10	9.0
	Jola	7	6.3
	Others	7	6.3
	Manjago	2	1.8
Place of Residence	West coast	47	42.3
	Greater Banjul	39	35.1
	North Bank region	11	9.9
	Upper River region	5	4.5
	Unknown	4	3.6
	Lower River region	3	2.7
	Central River region	2	1.8
Area of residence	Urban	69	62.2
	Rural	40	36.0
	Unknown	2	1.8

### Clinical features, physical examinations, and complications at presentation

Breathlessness (73.0%) was the most common clinical presentation, while chest pain was the

least represented complaint in about 10.0% of the children. (Table 2).

Table 2: Clinical features at presentation among the children with congenital heart diseases

Clinical features	Frequency	Percentage (%)
Breathlessness	81	73.0
Cough	66	59.5
Fever	64	57.7
Easy fatiguability	31	27.9
Cyanosis	28	25.2
Refusal to feeds	22	19.8
Exertional dyspnoea	20	18.9
Chest pain	11	9.9

Abnormal heart sounds (85.6%) were the most common examination findings, tachypnoea and tachycardia were also commonly represented. About one in every five of the children had finger clubbing, while pallor and pedal oedema were the least represented. Pneumonia (40.5%)

was the most common complication observed among the children and failure to thrive/ undernutrition, cyanotic spells as well as heart failure were the others. (Table 3) One in every five of the children with CHDs had features of Down syndrome.

Table 3: Examination findings and complications observed among the children with congenital heart diseases

Variables	Category	Frequency	Percentages (%)
Physical findings	Abnormal heart sound	95	85.6
	Tachypnea	72	64.9
	Tachycardia	62	56.8
	Digital clubbing	24	21.6
	Plethora	13	11.7
	Chest deformity	12	10.8
	Pallor	8	7.2
	Pedal oedema	4	3.6
Complications	Pneumonia	45	40.5
	FTT/Undernutrition	33	29.7
	Cyanotic spells	13	11.7
	Heart failure	12	10.8
Associated condition	Down syndrome	23	20.7

The majority of children (69.4%) were diagnosed with acyanotic congenital heart diseases, with ventricular septal defect (VSD) being the

most common lesion. Other acyanotic defects included atrial septal defect (ASD) and patent ductus arteriosus (PDA). Cyanotic congenital

heart diseases accounted for 30.6% of cases and comprised tetralogy of Fallot (TOF), transposition of the great arteries (TGA), and tricuspid atresia (TA). Two children (1.8%) present-

ed with complex cardiac anomalies, while eight cases (7.2%) could not be clearly classified. (Figure 1).

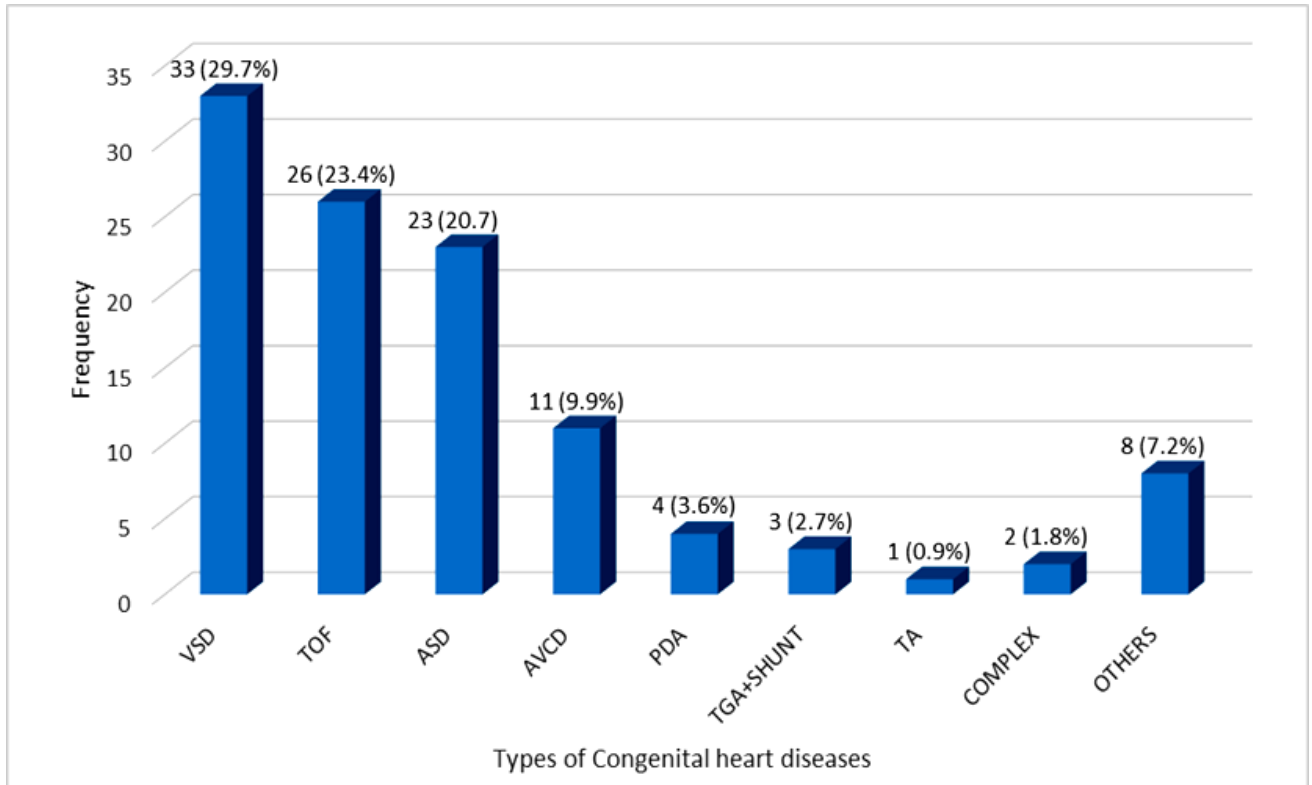


Figure 1: The spectrum of congenital heart diseases among children admitted to the Paediatric units of the Edward Francis Small Teaching Hospital, Banjul, The Gambia

Among the children, 23 (20.7%) had Down syndrome, and the most common associated cardiac lesions were atrial septal defect (ASD), atrio-

ventricular canal defect (AVCD), and ventricular septal defect (VSD). (Figure 2).

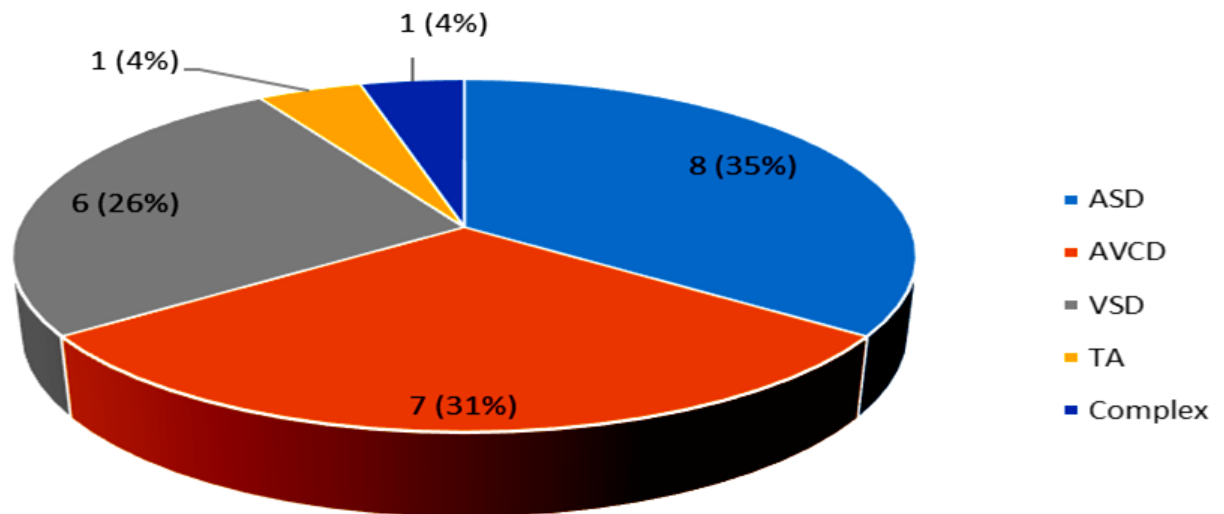


Figure 2: Spectrum of congenital cardiac lesions among the children with Down syndrome  
Outcomes of hospitalization in children with congenital heart disease

Sixty-eight children (61.3%) were clinically stable and discharged home, while 12 (10.8%) died during hospitalization. The remaining children were either discharged against medical advice (4; 3.6%) or transferred abroad to receive specialized treatment unavailable in The Gambia.

#### Factors associated with mortality among children with congenital heart diseases on bivariate analysis

Admitted school-aged children were significantly more likely to die from congenital heart diseases (CHDs) compared with younger children. Mortality occurred in 4 (36.4%) of the 11

school-aged children, compared with 8 (8.9%) of the 90 younger children ( $\chi^2 = 12.689$ ;  $p = 0.013$ ). Male sex was also significantly associated with mortality. Chest pain at presentation was significantly associated with mortality, with 4 (36.4%) of the 11 children presenting with chest pain dying, compared with 7 (7.0%) of the 100 children without chest pain ( $\chi^2 = 8.268$ ;  $p = 0.004$ ). Similarly, the presence of pallor at presentation (50.0% vs. 7.8%;  $\chi^2 = 13.732$ ;  $p < 0.001$ ) and failure to thrive/undernutrition (15.2% vs. 9.0%;  $\chi^2 = 10.127$ ;  $p = 0.018$ ) were significantly associated with mortality (Table 4).

Table 4: Factors associated with mortality among children with congenital heart diseases

Variables	Category	Died n=12 (%)	Alive n=99 (%)	$\chi^2$	p-value
Age	Neonates (0-28 days)	1 (8.3)	5 (5.1)	12.689	<b>0.013</b>
	Infants (one to <12 months)	5 (41.7)	42 (42.4)		
	Under-five (12 to 59 months)	2 (16.7)	43 (43.4)		
	School age ( $\geq 6$ )	4 (33.4)	9 (9.9)		
Sex	Male	10 (83.3)	53 (53.5)	3.872	<b>0.049</b>
	Female	2 (16.7)	46 (46.5)		
Residence	Urban	8 (66.7)	61 (61.6)	0.314	0.855
	Rural	4 (33.3)	36 (36.4)		
Clinical features	Breathlessness	10 (83.3)	71 (71.7)	0.732	0.392
	Cough	6 (50.0)	60 (60.6)	0.499	0.480
	Fever	6 (50.0)	58 (58.6)	0.323	0.570
	Easy fatiguability	4 (33.3)	27 (27.3)	0.195	0.659
	Cyanosis	3 (25.5)	25 (25.3)	0.000	0.985
	Refusal to feeds	1 (8.3)	21 (21.2)	1.117	0.291*
	Exertional dyspnoea	3 (25.5)	17 (17.2)	0.444	0.505*
	Chest pain	4 (33.3)	7 (7.1)	8.268	<b>0.004</b>
	Abnormal heart sound	11 (91.7)	84 (84.8)	0.403	0.525
	Tachypnea	10 (83.3)	62 (62.6)	2.014	0.156
	Tachycardia	8 (66.7)	55 (55.6)	0.538	0.463
	Digital clubbing	3 (25.0)	21 (21.2)	0.091	0.763*
	Plethora	1 (8.3)	12 (12.1)	0.149	0.700*
	Chest deformity	2 (16.7)	10 (10.1)	0.478	0.489
	Pallor	4 (33.3)	4 (4.0)	13.732	<b>&lt;0.001*</b>
	Pedal oedema	1 (8.3)	3 (3.0)	0.866	0.352*
	Pneumonia	5 (41.7)	40 (40.4)	0.007	0.933
	FTT/Undernutrition	5 (41.7)	28 (28.3)	10.127	<b>0.018</b>
	Cyanotic spells	3 (25.0)	10 (10.1)	2.298	0.130*
Heart failure	2 (16.7)	10 (10.1)	0.478	0.489*	

The figures in parentheses are percentages along the column; \* Fisher's exact test applied; Bolden figures denote statistical significance; FTT Failure to thrive

### Determinants of mortality among the children admitted for congenital heart disease

Factors found to be significantly associated with mortality on univariate analysis—namely school age, male sex, chest pain, pallor, and failure to thrive/undernutrition (Table 4)—were entered into a stepwise multivariable logistic

regression model. In the adjusted analysis, only pallor at presentation remained an independent predictor of mortality among children with congenital heart diseases (adjusted odds ratio [AOR] = 14.73; 95% CI: 2.35–92.37;  $p = 0.004$ ) (Table 5).

Table 5: Determinants of mortality among children with congenital heart diseases using Binary Logistic regression

Variables	Category	Mortality status		Adjusted Odds ratio	95% CI AOR
		Died # (%)	Survived # (%)		
Age		4 (33.4)	9 (9.9)	2.979	0.481 – 18.464
Sex	Male	10 (83.3)	53 (53.5)	3.786	0.646 – 22.184
	Female	2 (16.7)	46 (46.5)	1	
Chest pain		4 (33.3)	7 (7.1)	4.024	0.656 – 24.686
Pallor		4 (33.3)	4 (4.0)	14.731	2.349 – 92.373
FTT/ Undernutrition		5 (41.7)	28 (28.3)	1.761	0.396 – 7.836

SE Standard error; CI Confident interval; AOR Odds ratio; FTT Failure to thrive

### Discussion

This study has highlighted the prevalence, spectrum, clinical manifestations, hospital outcome and determinants of mortality among children admitted to the EFSTH, Banjul the Gambia over a two-year study period.

The prevalence of congenital cardiac lesions of 2.4% observed in this study is similar to 2.5% reported by Khasawneh et al (21) in Jordan and 2.2% reported by Misra et al (22) in eastern Uttar Pradesh and 2.6% by Kapoor and Gupta in India. (23) The prevalence of 2.4% was significantly higher than 0.88% reported by Chinawa et al (24) from Enugu, south east Nigeria, and <1.0% from developed countries. (3) The

relative higher prevalence reported in the present study and other less developed countries may be related to fact that EFSTH, the study site is the only tertiary health facility in the Gambia, hence it the main referral centre for all cases of confirmed and suspected cardiac lesions. Also, possibility of unrecognized maternal (congenital) infections and micronutrient deficiencies contributing to high prevalence of CHD in LMICs has also been proposed (25).

During the study period, approximately one of every 10 children admitted for CHDs died, this in-hospital mortality rate of 10.8% was similar to reports from other developing

countries (36). The survivors are presently on conservative medical treatment awaiting definitive surgical repair which unfortunately is not available in the Gambia and most facilities in other developing countries. (16, 39-40) In places where facilities for open heart surgical interventions are available, the mortality from CHDs was reported to be significantly lower 2.5% and mostly from complex heart lesions. (41) Facilities for definitive interventions in children with CHD are often beyond the reach of the average family in developing countries where direct (out-of-pocket) payment for health services is the norm (16, 39-40). This implies that making facilities for repairs and other interventions available and affordable for family with children with CHDs will go a long way in ensuring quality survival of these children. In this study, among children with unrepaired CHDs managed conservatively, pallor was an independent predictor of mortality. Pallor may suggest severe tissue hypoperfusion for a number of reasons including cardiac decompensation, sepsis and cardiogenic shock. Cardiac arrhythmias, pulmonary hypertension and thromboembolic events are other factors associated with mortality which may manifest as pallor (37). Though the number of children with pallor in this study is relatively small, nevertheless, pallor in children with unrepaired CHDs may connote poor prognosis,

Worthy of note from this study is that the median age of diagnosis of CHD was 2.4 months

with majority diagnosed in infancy. This agrees with the report from other workers (20-25). Also male preponderance was observed among the children with CHDs which agrees with most of other reports from developing (7-11) and developed countries (2-3), however, some series reported female preponderance (25-26). The reason for the male preponderance observed in this study as reported by other workers is not clear, however according to the so-called Yentl syndrome which suggest that in similar physical conditions females are less likely to be referred, less likely to undergo diagnostic investigation and receive treatment (27). Studies to validate this suggestion yielded contradictory results. For example, Roeters van Lennep and colleagues (28) found no evidence for a different approach to care received by females compared to males. There is also reported gender difference in the various specific type of CHDs. For instance, ASD and Pulmonary stenosis have been reported to be more common in females, while VSD were reported more in males. (28-29) More population-based studies looking at gender-specific prevalence of CHDs in children will be worthwhile.

As reported by other workers in developed (2-3) and developing countries (7-11, 20-23), VSD was the most common CHDs observed in our study. Reason for this is unclear, however, like other congenital cardiac and non-cardiac anomalies combination of genetic and epigenetic factors as well as environmental

factors contribute to congenital lesions in children. (29-30) since the genetic factors may not be modifiable the implication is that environmental factors like exposure to ionizing agents, teratogens, viral and congenital infections and infestations, low birth weight, preterm deliveries etc. should be prevented to reduce the burden of CHDs. Down syndrome was the only genetic abnormalities identified among the children observed in one-fifth of the children and VSD and AVCD were the most common cardiac lesion observed among the children with Down syndrome. This is similarly reported by other workers. (31-33) Down syndrome being the most common chromosomal abnormalities in children reported in 1 in 600 to 800 is a leading associated factor with CHD in children, as CHD has been reported in 40-60% of these children and even up to 75% of those admitted in the hospital. (32) This implies that routine echocardiography assessment should be done in all children with Down syndrome for early detection and management of cardiac lesions in them.

Breathlessness and abnormal heart sounds were the most common clinical manifestations of CHDs in children. These findings are similarly reported by other workers (10-12, 31). Breathlessness in children with CHDs may occur from a number of pathogenetic pathways. (34) It may be related to direct effects of the cardiac lesions for example left to right shunt with the resultant 'flooding' of the lung, pulmonary oedema and cardiac failure. (34) It may

also be related to the physiological consequence of the cardiac lesions such as polycythemia associated with cyanotic CHDs resulting in polycythemia (35). Furthermore, breathlessness may occur from recurrent chest infection which children with certain CHDs are prone to (34). This implies that clinicians should have a high index of suspicion of CHDs in children with breathlessness especially if it is recurrent. Other important manifestation of CHDs among our study participants was undernutrition and or failure to thrive observed in about one-third of the children. This is similarly reported by other workers (10-12, 36). Children with CHDs are likely not thrive well as they expend lots of energy from breathlessness at the expense of growth (37). Also, FTT in children with CHDs may be due to a combination of low energy intakes and high energy requirements resulting in insufficient energy for growth (37). Recurrent chest infection and cardiac decompensation with the resultant tissue hypoperfusion and hypoxia also contribute significantly to poor growth and failure to thrive (37). Studies have also demonstrated that repair of congenital cardiac lesions in children leads to improvement in growth, wellbeing and quality of life of these children. (38) This implies that early diagnosis and prompt intervention is ideal in children with CHD for better outcomes.

This study highlights the prevalence and spectrum of childhood CHDs in the only tertiary

referral centre in the Gambia using quality-assured 2-D echocardiography. It described the clinical manifestations and complications observed among the children as well as factors associated with mortality in these children. These constitute the strengths of this study, we however appreciate the fact that further echocardiography characterization of the cases of CHDs to ascertain ejection fraction, chamber structure and functions, pulmonary pressure etc. which may affect prognosis was not done in this study. Also, population-based study to capture children with asymptomatic CHDs or those who may not present to the hospital will be more revealing.

In conclusion, 24 per every 1000 childhood admissions at the EFSTH, the Gambia had CHDs and VSD was the most common type. Breathlessness, abnormal heart sounds and cough were the most common manifestations, while pneumonia and FTT/undernutrition were the most common complications. One in ten of the children with these cardiac lesions died, and school age, FTT and pallor were associated with mortality. Early diagnosis and making affordable and accessible intervention within the reach of the family of these children will reduce of huge burden of CHDs in the Gambia and indeed other developing countries.

### List of abbreviations

ASD atrial septal defect

VSD Ventricular septal defect

AVCD Atrioventricular Canal Defect

TOF Tetralogy of Fallot

CHDs Congenital heart Diseases

TA Truncus Arteriosus

PDA Patent Ductus Arteriosus

FTT Failure to thrive

EFSTH Edward Francis Small Teaching Hospital

LMICs Low- and Middle-Income Countries

### Declarations

**Ethical Considerations:** This study was approved by the Ethics and Research Committee of the Edward Francis Small Teaching Hospital, Banjul, The Gambia

**Conflict of interest:** The authors declare no conflict of interest

**Authors' contribution:** KE, LM, ML conceptualised the study, collected data and participated in the management of the patients. KE, BPK analysed the data, KE wrote the first draft of the manuscript. All the authors contributed to the critical review of the manuscript and approved the final draft of the manuscript

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