

Caring For Children With Congenital Heart Diseases: Economic Burden Of Pre-Surgical Treatment On Nigerian Families

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Abstract

Background Congenital Heart Disease (CHD) places an enormous economic burden on families of affected children in Nigeria. This study sought to determine the healthcare costs of pre-surgical management of CHD and describe its effects on the family's income.

Methods Using a semi-structured interviewer-administered questionnaire, family income, type of CHD, co-morbidity, healthcare payment mechanism and healthcare cost were investigated among 121 families with CHD children. Indicators of Catastrophic Health Expenditure (CHE); healthcare spending in excess of 10% family income were calculated. Factors associated with increased healthcare spending in CHD management were explored using the Kruskal Wallis test of significance.

Results Of the 121 parents interviewed, about 80% paid for healthcare using out-of-pocket payment mechanism. Mean annual total cost of healthcare was ₦87,951 ± ₦120,213 (\$244.31 ± \$333.92) with direct medical care accounting for 81.0% of this total annual cost. Mean annual consultation, medication, investigation and admission cost were ₦5,515 (\$15.32), ₦57,882 (\$160.78), ₦30,462 (\$84.62) and ₦87,789 (\$243.86) respectively. Mean estimated annual indirect cost was ₦19,233 ± ₦31,722 (\$53.42 ± \$88.12). Incidence of CHE was 35.5% while catastrophic overshoot and mean positive overshoot attributable to CHD healthcare cost were 6.5% and 32.9% of family income respectively. Healthcare cost was significantly higher in families of children with co-morbidities ($p = 0.016$) and those who suffered financial catastrophe ($p = 0.001$). Health insurance did not significantly reduce healthcare spending among the insured.

Conclusion The economic burden of pre-surgical management of children with CHD is high in Nigeria. There is the need to scale up the inclusion of CHD under the National health insurance scheme.

Background

Congenital heart disease (CHD) is a structural abnormality of the heart and/or great vessels that is present at birth [1]. The birth prevalence of CHD is reported to be on the increase, with rates of up to 9.3/1000 live births globally [2]. It remains the commonest birth defect and is an important cause of childhood mortality worldwide [1–3]. In Nigeria, low prenatal screening for CHD leads to late diagnosis and subsequent delay in surgical intervention which results in increased morbidity and mortality from CHD [4, 5].

The definitive management of CHD in most cases is surgical correction. In Nigeria however, the availability of services needed for definitive management of CHD exist only in very limited public and private health facilities [6, 7]. In health facilities where these services are available, they are unaffordable to most families of children with CHD [6, 7]. The alternative offered by medical tourism, where these services can be sourced abroad is also hindered by cost [8]. Thus affected children and their parents travel very long distances to attend cardiac missions within the country. Cardiac missions are arrangements in which foreign medical experts come into the country with some medical equipment not

available locally, to offer surgical services for cardiac problems within a limited period [9, 10]. These services are offered free to patients, but the missions are organized and funded by Non-government Organizations (NGO), international agencies and sometimes by state governments of Nigeria [8–10]. During the cardiac mission exercise, patients are screened and assessed for suitability for surgery. However, only very few patients are selected for surgical intervention during each visit [8–10].

Prior to definitive intervention, the conservative medical management of a child with congenital heart disease involves frequent outpatient clinic visits, prolonged drug use, repeated investigations and regular hospitalizations due to complications such as heart failure, pulmonary hypertension, hyper-cyanotic spells and severe polycythaemia requiring exchange blood transfusion[5]. This continuous need for healthcare has devastating and long-lasting consequences especially for poor households, both through income loss and high medical expenditures [11–13]. In the absence of a protective health financing mechanism, the full financial burden of caring for children with CHD is borne by their families through direct out-of-pocket (OOP) expenditure in most African settings [13, 14].

Universal health coverage (UHC) stipulates that all individuals should have access to quality health services without exposing them to financial catastrophe [15–17]. Catastrophic health expenditure (CHE) when paying for health care is often described as health care spending that exceeds a pre-defined threshold; usually 10% of household income [18–22]. It is believed that beyond this threshold, most households cut down on spending on food and other basic needs, borrow money and sell household assets to pay for health care or at times, completely avoid seeking health care [18–23]. The presence of a chronic disease places a huge financial demand on families due to the need for long-term treatment and care [12–14]. Low socioeconomic status, lack of health insurance, and recurrent hospitalization have been associated with increased risk of catastrophic health expenditure (CHE) in low and middle income countries[12–14].

There is a paucity of studies on the economic burden of CHD on Nigerian families. Thus, the aim of this study was to determine the direct and indirect medical costs of pre-surgical treatment of congenital heart diseases and describe the catastrophic effects of expenditure on the family income.

Methods

Study setting and design

This was a cross sectional study conducted during a cardiac mission organized to screen pre diagnosed children with CHD and determine their suitability for surgical intervention. It held in Uyo, Akwa Ibom State, south-south Nigeria in May 2019 and explored healthcare expenditure related to the care of a child with CHD, one year (1st May 2018 to 30th April 2019) prior to the cardiac mission in each family that participated in the study.

Study population

Children living in the Niger delta region of Nigeria with a prior diagnosis of CHD were invited for a free cardiac screening exercise and selection for future surgical intervention. Parents of children with CHD who attended the mission were recruited to participate in the study. Inclusion criteria included all parents of children with CHD who had been attending a cardiology outpatient clinic for at least 3 months.

Data collection

Using a semi-structured pretested interviewer-administered questionnaire, each family represented by either the father or mother who consented to participate in the study were interviewed. The questionnaire consisted of four sections. The first section explored the socio-demographic characteristics of the study participants, such as age, gender, occupation, income and educational status. The socioeconomic status was determined using the socioeconomic classification for children by Oyedeji *et al* [24]. Section Two enquired about the household income and payment mechanism employed while making health expenditure. Household income was defined as the total income by all members of the household; not just income of the head of the household. Section Three investigated household financial expenditure on the healthcare for the child with CHD in the one year prior to the cardiac mission. Healthcare expenditure included Direct and Indirect costs [25]. Direct costs refer to expenses made on the prevention, diagnosis and treatment of a disease or health-related condition [25, 26]. Direct cost was explored by estimating the direct medical and direct non-medical cost. Direct medical cost estimated the costs of registration, consultation, medications, investigations and hospitalization while direct non-medical cost was estimated by exploring the transportation, accommodation and feeding cost of the child and caregiver while seeking healthcare for the child with CHD. The last section assessed the indirect cost, which is defined as all costs incurred from or related to productivity loss due to illness, disability or death of a sick person whether in a paid or unpaid capacity [26–28]. Indirect cost includes reduction in income due to missed workdays/hours, decreased productivity at work and for unpaid work. Indirect cost in this study was estimated in terms of man-hour loss, that is, time spent at the hospital during cardiac clinic visits, investigation and/or hospitalizations by the caregiver of the child with CHD

Data analysis

Analysis was done to uncover the demographics, earnings and total consumption expenditure and health care expenditure of the households. Two types of costs were computed as response variables: the Direct costs and Indirect costs. Direct costs were divided into direct medical and direct non-medical costs. The direct medical costs were computed by evaluating the costs of cardiac medications, health care expenditures on outpatient appointments (hospital registration and out-patient consultation fees), emergency care visits, laboratory investigations and hospitalizations incurred over the last one year. Direct non-medical cost was calculated as additional costs incurred in accessing health care such as transportation fare, accommodation and feeding costs by the child and caregiver.

Indirect costs were assessed as earnings lost by the parents or caregivers while seeking medical care for the child. This included the loss of man hours from work leading to a decline in productivity and subsequently, a reduction in income. To assess the indirect costs, the productivity losses of

parents/caregivers was calculated [29]. To determine this, the average daily income (ADI) of the parents was determined for both formal and informal workers. Next, the number of days (DA) that caregivers were absent from work due to the need to take the child to the hospital for outpatient and/or inpatient visits was obtained. The product of ADI and DA was calculated to give an estimate of indirect health care cost.

The proportion of the annual household income spent on seeking healthcare for the child with CHD was computed by dividing the total household annual income by total annual cost of health care. The mean proportion of family income spent on the healthcare of a child with CHD in the study population was computed to obtain the Catastrophic Overshoot. Catastrophic health expenditure (CHE) was defined as healthcare spending in excess of 10% family income [30]. Among families that spent greater than 10% of family income on the care of this condition, the Mean Positive Overshoot (MPO) was calculated by estimating the mean proportion of family income spent above the 10% threshold.

Drivers of healthcare cost for this condition were identified using non-parametric statistical tests (Kruskal Wallis and Mann Whitney U tests).

Data was analyzed using Statistical Package for the Social Sciences (SPSS) for Windows version 22. Statistical significance was determined at p-Value < 0.05 and all costs were recorded in Nigerian naira (₦) and converted to American Dollar (\$) based on an exchange rate of 1US\$ to ₦360 (as at May 2018).

Ethical considerations

Ethical approval for the study was granted by the Research and Ethics Committee of the University of Uyo Teaching Hospital, Uyo, Nigeria (Committee reference number- UUTH/AD/S/96/VOL XXI/377). Written informed consent was obtained from each study participant before the start of the study.

Results

Socio-demographic characteristics

Out of the 154 parents who brought their children to the cardiac mission, 121 met the inclusion criteria and were recruited into the study. A total of 121 children, 63 males and 58 females, with congenital heart diseases were seen, giving a male/female ratio of 1.1: 1. Their ages ranged from 2 to 180 months with a mean of 42.3 ± 41.9 months. Majority of the children were first born children (33.1%) and belonged to the high socioeconomic class. (see Table1) About a fifth had health insurance (14.9% with social insurance (NHIS) and 4.1% with private insurance) while the rest paid for healthcare using the out-of-pocket payment mechanism (81.0%).

Table 1
Socio-demographic characteristics of Children in the Study

Characteristics	Frequency (N = 121)	Percent (%)
Sex		
Male	63	52.1
Female	58	47.9
Age (years)		
< 1 year	32	26.4
1–5 years	57	47.2
6–10 years	22	18.2
11–15 years	10	8.2
Religion		
Christianity	119	98.3
Islam	2	1.7
Family Type		
Monogamous	118	97.5
Polygamous	3	2.5
Birth Order of Child		
First	40	33.1
Second	37	30.6
Third	24	19.8
Fourth	11	9.1
Fifth and Higher orders	9	7.4
Number of children in Family		
1–2	57	47.1
3–4	49	40.5
≥ 5	15	12.4
Child Socioeconomic Status		
Low SES	12	10.0
Middle SES	36	29.8

Characteristics	Frequency (N = 121)	Percent (%)
High SES	73	60.2

Features of Congenital heart disease among children

Duration of diagnosis of the heart condition ranged from 1 to 168 months, median of 12.0 months. Acyanotic congenital heart diseases accounted for 79.3%, while 20.7% of the children had Cyanotic congenital heart condition. Almost half (49.2%) had a co-morbidity which included heart failure (32.8%), pulmonary hypertension (12.3%) and Down syndrome (23.8%). Medications used by the children included Spironolactone (28.9%), Lasix (24.0%), Captopril (13.2%), Propranolol (5.8%) and Enalapril (5.0%). Mean duration on medication was 8.6 ± 19.5 months.

Direct medical cost

Direct medical cost accounted for 81.0% of the mean total annual cost of caring for the children with congenital heart disease. The annual direct medical cost ranged from ₦150 (\$0.42) up to ₦766,000 (\$2,123.78) with a mean cost of N86,400 \pm ₦115,028 (\$240.00 \pm \$319.52) per annum. The mean annual cost of consultation was N5,515 (\$15.30) ranging between as low as N50 (\$0.14) and as high as N30,000 (\$83.30). Number of clinic visits ranged from 0 to 30 visits with median of 3 visits in the last one year. Fifty three children (43.8%) were on medication, however only 34 children (28.1%) reportedly made expenditure in procuring their drugs. The average amount spent on procuring drugs was ₦57,882 \pm ₦70,033 (\$160.78 \pm \$194.54) in the year under review. (Table 2)

Table 2
Mean Annual Medical costs of treatment of children with Congenital heart disease

Variable	Mean(₦)	Standard deviation(₦)	Range(₦)
Total Healthcare Cost	87,951	120,213	150–766,000
Direct Healthcare cost			
Direct Medical Cost	86,400	115,028	200–712,000
Direct Non-Medical Cost	10,638	18,370	150–132,000
Indirect Cost (Productivity Loss)	19,223	31,722	500–207,000
Mother/father out of work	5,515	7,768	50–30,000
Breakdown of Direct Medical costs	57,882	70,033	6,000–360,000
Consultation	30,462	35,313	500–230,000
Drugs	87,789	116,807	3,000–620,000
Investigation	7,406	13,553	150–110,000
Admission	5,465	8,465	200–48,000
Breakdown of Direct Non-medical costs	23,821	22,176	5,000–100,000
Transportation	68,666	45,003	36,000– 20,000
Food	4,236	3,699	900–16,000
Investigation costs	5,214	3,598	1000–10,000
Echocardiogram	3,600	3,815	500–150,000
Chest CT Scan	5,021	5,418	1,100–18,000
Chest X-ray	5,250	6,739	500–15,000
Electrocardiogram	17,000	15,556	5,000–47,000
Full blood count			
Serum Electrolyte & Urea			
Blood Culture			
Blood transfusion			

The major investigations included Echocardiogram, Electrocardiograph and Chest radiograph which were done by 70.2%, 12.4% and 40.5% of the children respectively. Multiple sessions of Echocardiogram and Chest radiograph were reported with 10.0% of children having at least 3 sessions of Echocardiogram. The cost of one session of Echocardiogram ranged from ₦5,000 (\$13.89) to ₦40,000 (\$111.11). Averagely, caregivers expended ₦23,821 ± ₦22,176 (\$66.17 ± \$61.60) on Echocardiogram, ₦4,236 ± ₦3,699

(\$11.77 ± \$10.27) on Chest radiograph and ₦5,214 ± ₦3,598 (\$14.48 ± \$9.99) on Electrocardiogram in the year under review. Mean amount spent on investigations was ₦30,462 ± ₦35,313 (\$84.62 ± \$98.09) with estimated amount ranging between ₦500 (\$1.38) and ₦230,000 (\$638.89). The other investigations done included Full blood count, serum Electrolyte and Urea, Blood culture and Cardiac CT Scan. (Table 2)

Fifty-one children (42.1%) were hospitalized in the year under review with episodes of hospitalization ranging between 1 and 10 episodes with a median of 1 episode. Mean hospital stay was 7 ± 4 days. Cost of hospitalization ranged between ₦3,000 (\$8.33) and ₦620,000 (\$1722.22) with a mean of ₦87,789 (\$243.86) and standard deviation of ₦116,807 (\$324.46).

Direct non-medical costs

The mean direct non-medical cost was ₦10,638 (\$29.6) with transportation accounting for most of this cost. The transportation cost for clinic visit range from ₦150 – ₦110,000 (\$0.42 - \$305.55) with a mean of ₦7,406 ± ₦13,553 (\$20.57 ± \$37.65). Most children (81.8%) got to the different hospitals where they were cared for by public transportation. Average amount spent on food while on hospital visit or while on admission for the child and caregiver was ₦5,465 ± ₦8,465 (\$15.18 ± \$23.51) in the year under review. (Table 2)

Indirect Cost

Mothers, Guardians and father took 84.3%, 10.7% and 5.0% of the children to hospitals for their clinic visits respectively. While on admission, mothers and guardians missed days at work to care for their children. Mean annual productivity loss was ₦19,233 ± ₦31,722 (\$53.42 ± \$88.12) and ranged from ₦500 (\$1.38) to ₦207,000 (\$575.00).

Total Cost

Total cost of health care in the year under review ranged between ₦150 (\$0.42) and ₦766,000 (\$2,127.8) with a mean total cost of ₦87,951 ± ₦120,213 (\$244.31 ± ₦333.92). The estimated total sum expended by the 121 households in the study in the conservative care of the children was ₦10,202,330.00 (\$28,339.80) in the last one year under review.

The total annual household income ranged from ₦180,000 (\$500) to ₦7,200,000 (\$20,000) with a mean of ₦1,333,983 ± ₦1,350,266 (\$3,705.51 ± \$3,750.74). About 64.5% of households spent less than 10% of their total annual household income while caring for children with CHD (Fig. 1).

Effect of healthcare expenses on households

The proportion of households who suffered Catastrophic Health Expenditure (CHE) i.e. that spent more than 10% of their annual income on health care was 35.5%. The severity of CHE among the study population as measured by the Catastrophic Overshoot showed that averagely, the percentage spending on health exceeded the predefined threshold of 10% income by 6.5% of the annual household income. The Mean Positive Overshoot (MPO) which measures overshoot among households that suffers

catastrophic expenditure was 32.9% and ranged from 0.26% to a 237.7% of the annual household income. A tenth of the households spent greater than 50% of their household income on the care of children with CHD (Fig. 1).

Relationship between socio-demographic, clinical variables and cost of care

The results of Kruskal Wallis and Mann Whitney U test shown in Table 3 demonstrates a significant difference in the median costs across the direct medical, direct non-medical and total costs between households who suffered financial catastrophe and those who did not ($p = 0.001$). The presence of co-morbidities (heart failure and pulmonary hypertension) significantly influenced the cost of healthcare to these families. Duration of clinic attendance caused significant difference in the amount expended by families on the direct non-medical cost. It was however surprising to note that families on health insurance were not significantly different from those who paid by the out of pocket payment mechanism in any of the health care cost subhead.

Table 3

Relationship between direct medical, direct non-medical and total cost of CHD and sociodemographic, clinical variables

Variable	Direct Medical Cost		Direct Non-Medical Cost		Total Cost	
	Median cost in naira (₦) (Range)	p-Value	Median cost in naira (₦) (Range)	p-Value	Median Cost in naira (₦) (Range)	p-Value
Age group						
< 1 years	42200 (250–44320)	0.685	2100 (300–40000)	0.487	40100 (250–463200)	0.538
1–5 years	46600(200–712000)		6000 (150–132000)		43000 (150–766000)	
6–10 years	46000(250–412000)		3500 (200–45000)		43500 (250–416800)	
> 10 years	65875 (5500–95000)		3000 (300–21000)		32600 (400–116000)	
Socioeconomic class						
Lower	13775 (500–81000)	0.110	2400 (400–6000)	0.304	14675(500–30913)	0.196
Middle	54600 (250–712000)		2700 (150–132000)		50850 (150–766000)	
Upper	51500 (200–443200)		5000 (300–67200)		46600 (200–463200)	
Mode of Payment						
Health Insurance	60500(1500–285000)	0.793	6500 (300–67200)	0.336	49000 (1500-301000)	0.639
OOP	42200(200–712000)		4100 (150–132000)		40000 (150–766000)	
Duration of Cardiology clinic attendance						
< 1 year	42200(250–712000)	0.980	2900 (150–54000)	0.001*	40000(150–766000)	0.383
1–5 years	40000 (200–216500)		6000 (300–13200)		28600 (200–300500)	
6–10 years	81000 (250–412000)		6600 (200–45000)		95000 (450–416800)	
Effect of Payment						

Variable	Direct Medical Cost		Direct Non-Medical Cost		Total Cost	
	Median cost in naira (₦) (Range)	p-Value	Median cost in naira (₦) (Range)	p-Value	Median Cost in naira (₦) (Range)	p-Value
CHE Household	127000 (12100–712000)	0.001*	8400 (300–132000)	0.001*	142400 (12700–766000)	0.001*
Non-CHE Household	13000 (200–197500)		2650 (150–67200)		15850 (150–209500)	
Co-Morbidity						
Present	65375 (200–443200)	0.025*	6850 (200–45000)	0.007*	63000 (150–463200)	0.016*
Absent	40000 (250–712000)		2250 (150–132000)		30300 (150–766000)	

Table 3

Relationship between direct medical, direct non-medical and total cost of CHD and sociodemographic, clinical variables ctd

Variable	Direct Medical Cost		Direct Non-Medical Cost		Total Cost	
	Median cost in naira (₦) (Range)	p-Value	Median cost in naira (₦) (Range)	p-Value	Median Cost in naira (₦) (Range)	p-Value
Co-morbidity_Heart Failure						
Yes	124600 (3500–443200)	0.001*	8100 (300–45000)	0.001*	122750 (2000–461200)	0.001*
No	25150 (200–712000)		2400 (150–132000)		23200 (150–760000)	
Co-morbidity_PHTN						
Yes	69700 (3500–412000)	0.308	7650 (1400–45000)	0.032*	75700 (8600–416800)	0.043*
No	44350 (200–712000)		3400 (150–13200)		40000 (150–766000)	
Co-morbidity_Downs						
Yes	40000 (200–412000)	0.644	6000 (200–40000)	0.279	45000 (200–416800)	0.740
No	49250 (250–712000)		3000 (150–132000)		43000 (150–766000)	
Type of Congenital Heart Disease						
Acyanotic	40000 (200–712000)	0.422	3400 (200–54000)	0.180	39200 (200–766000)	0.226
Cyanotic	56800 (250–334400)		6500 (150–132000)		63000 (150–382400)	
*Statistically significant						

Discussion

In our study, the mean total cost of healthcare was about \$240 per patient per annum, with direct medical costs accounting for 81% of the total cost. Hospitalization costs was found to be a major contributor to the direct medical cost as almost half of the children in the study had been hospitalized at least once in the year under review. Direct health care cost expended for hospitalization has been found to be responsible for more than half of all medical costs for children with birth defects such as congenital heart diseases [31, 32]. On an average, drugs and investigations were responsible for 45% of total direct cost

each among children who were compliant with medications and had investigations when prescribed. The long term needs for medication, periodic investigative assessment and recurrent hospitalization associated with CHD further highlights the financial burden borne by the families of the affected children.

Catastrophic health expenditure (CHE) occurs when households spend a large proportion of their income (above a threshold usually 10% income) to pay for healthcare [15]. In this study, the incidence of CHE among families interviewed was 35.5%. This finding is similar to what was reported by Sadoh *et al* [33] in Benin, where about 34.4% of families spent greater than 10% of income on care of children with chronic heart failure. This implies that more than a third of families with children with CHD spend more than 10% of the families' annual income on the healthcare of only one child in the family. This demonstrates the potential effect that the presence of this condition has on the welfare of families. Azzani *et al* [34] in their study showed that socioeconomic status, incidence of hospitalization, and presence of a family member with a chronic illness were significant factors associated with household CHE. In the presence of CHE, families may have to cut down on basic needs like education, feeding, clothing and compromise living standards to cope with the long term cost of healthcare [35, 36]. With 3 as the median number of children in the family in this study, it means other children may suffer neglect, lack and low living standards because of a sibling with CHD.

The Catastrophic Overshoot and Mean Positive Overshoot show that a third of the families spent far above the 10% income threshold on the care of these children. Furthermore, almost 1 in every 10 families spent greater than 50% of their annual income on CHD treatment. Affected families exceeded this threshold by as low as 0.26% and as high as 237.7%. This certainly means that a proportion of these families will spend far above their annual income to care for the affected child and may even be forced to borrow money. When there is a significant proportion of out of pocket house hold expenses spent on health, it is usually at the expense of non- health goods and services such as care of other non-ill siblings at home [32, 33]. In these cases, health services could be paid for with family savings, loans or sale of assets; all which put a financial strain on the family income [37]. This validates the impoverishing effect of healthcare cost as families now utilize future earnings in replacing household assets and paying back debts and interest.

Some Nigerian authors have reported that co-morbidities like congestive cardiac failure (CCF) in association with CHD increases cost thereby leading to financial catastrophe in the families with children with CHD [37, 38]. This study similarly identified CCF as a significant driver of healthcare cost in these children, significantly increasing both the direct and indirect cost. CCF is a common co-morbidity in children with CHD which results from the pulmonary over-circulation that occurs following the left to right shunting of blood through these defects. When longstanding and uncontrolled, CCF leads to recurrent chest infections, pulmonary hypertension and failure to thrive in affected children [39]. This finding was not surprising as the presence of CCF leads to frequent trips to the hospital either on an outpatient basis or for emergency in-patient care, thus increasing all categories of healthcare cost. The cost of treatment of a child with chronic heart failure has been described as enormous by Sadoh *et al* [33] where greater than 25% of the families seen in their study spent over 10% of their income on anti-failure medications.

Duration of cardiology clinic attendance was also found to significantly increase the direct non-medical cost. The results illustrate that as the duration of clinic attendance increases, the direct non-medical cost becomes significantly higher. Regular and frequent clinic attendance was found to increase the financial burden on the families due to expenses made on transportation, feeding and outpatient consultation fees by Sadoh *et al* [33] in their study on children with chronic heart failure. In their study, the authors reported that as high as 8% of the family income was spent on transportation, and postulated that this was due to frequent trips to the hospital for drug refills. Transportation costs however did not impact on direct medical cost in the present study. This could be due to the fact that some families spend more at the initial stage of diagnosis of this condition on investigation, medication and sometimes on hospitalization in order to plan appropriate treatment. Also over time, the older patients may also forgo clinic visitations especially when they have no associated co-morbidities thus cutting down on medical cost.

The cost of healthcare was not significantly associated with social class unlike the study by Sadoh *et al* [33] who noted higher expenditures among the lower social economic class compared to those in the middle or high social class. This difference could be attributed to the fact that their study was carried out in a hospital setting and involved a smaller sample size as compared to the present study. It was also surprising to note that expenditures made by insured families were not significantly different from those by families paying for healthcare with out-of-pocket payment mechanism. Health insurance in Nigeria is a social health insurance model operated by the National health insurance scheme which covers a healthcare of a family; which consists of the principal, his/her spouse and a maximum of four children below the ages of 18 years [40, 41]. A person below the age of 18 years is regarded as a minor and is not allowed to register on his or her own; however newborn infants up to the ages of 3 months are covered by the health insurance schemes of their mothers [40]. Thereafter, the enrollment of children into the NHIS is solely dependent on their parents or guardians [40, 41]. Low enrollment rates into health insurance schemes were described by Onwujekwu *et al* [13] who noted that only 1% of the households in a survey in South Western Nigeria had a primary adult registered under the NHIS. Delayed enrollment of children into a health insurance scheme could be a reason why most of the children in an insured family are not enjoying discounted cost of healthcare.

This study attempts to fill the gap created by drought of research into economic burden of healthcare cost among families of children with CHD, however, it is not without limitations. First, the study attempted to estimate healthcare in the group under investigation over a period of one year prior to the study, this could be affected by recall bias. Since the conservative care in children with CHD is a continuous care, participants were patiently interrogated from the most recent events to more distant events. Secondly, there is a likelihood of underestimation of healthcare cost in this study since only children who sought one form of care before the medical mission were interviewed, the cost of care for families who forgo care was not calculated thus leading to an underestimation. Lastly the study did not explore the coping strategies employed by these families in mitigating the enormous economic burden forced on families with children with CHD.

Conclusion

The economic burden of pre-surgical management of children with CHD is high in Nigeria. There is the need for the establishment of many centers of excellence for the definitive management of congenital cardiac disease. It is also necessary that the NHIS continues to evolve innovative programs that would scale up the inclusion of specific disease like CHD thereby cushioning the effect of their healthcare cost on affected families.

Declarations

Ethical approval and consent to participate

Ethical approval for the study was granted by the Research and Ethics Committee of the University of Uyo Teaching Hospital, Uyo, Nigeria (Committee reference number - UUTH/AD/S/96/VOL XXI/377). Written informed consent was obtained from each study participant before the start of the study.

Consent for publication

Not applicable

Availability of data and materials

The data sets used and/or analyzed during the current study are available from the corresponding author upon reasonable request.

Competing Interests

The authors declare they have no competing interests

Note

OOP: Out of Pocket

CHE

Catastrophic Health Expenditure

PHTN

Pulmonary Hypertension

Note

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Authors contributions

All authors were all involved in the conception and design of the study and the acquisition and interpretation of the data. COD and ADA wrote the first draft of the manuscript. ADA, WG and FA conducted the data analysis. IA revised the manuscript. All the authors critically reviewed the manuscript and approved the final version to be published.

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Tables

Table 1: Socio-demographic characteristics of Children in the Study

Characteristics	Frequency (N = 121)	Percent (%)
Sex		
Male	63	52.1
Female	58	47.9
Age (years)		
< 1 year	32	26.4
1 - 5 years	57	47.2
6 - 10 years	22	18.2
11 - 15 years	10	8.2
Religion		
Christianity	119	98.3
Islam	2	1.7
Family Type		
Monogamous	118	97.5
Polygamous	3	2.5
Birth Order of Child		
First	40	33.1
Second	37	30.6
Third	24	19.8
Fourth	11	9.1
Fifth and Higher orders	9	7.4
Number of children in Family		
1 - 2	57	47.1
3 - 4	49	40.5
≥ 5	15	12.4
Child Socioeconomic Status		
Low SES	12	10.0
Middle SES	36	29.8
High SES	73	60.2

Table 2: Mean Annual Medical costs of treatment of children with Congenital heart disease

Variable	Mean(₹)	Standard deviation(₹)	Range(₹)
Total Healthcare Cost	87,951	120,213	150 - 766,000
Direct Healthcare cost			
Direct Medical Cost	86,400	115,028	200 - 712,000
Direct Non-Medical Cost	10,638	18,370	150 - 132,000
Indirect Cost (Productivity Loss)			
Mother/father out of work	19,223	31,722	500 - 207,000
Breakdown of Direct Medical costs			
Consultation	5,515	7,768	50 - 30,000
Drugs	57,882	70,033	6,000 - 360,000
Investigation	30,462	35,313	500 - 230,000
Admission	87,789	116,807	3,000 - 620,000
Breakdown of Direct Non-medical costs			
Transportation	7,406	13,553	150 - 110,000
Food	5,465	8,465	200 - 48,000
Investigation costs			
Echocardiogram	23,821	22,176	5,000 - 100,000
Chest CT Scan	68,666	45,003	36,000- 20,000
Chest X-ray	4,236	3,699	900 - 16,000
Electrocardiogram	5,214	3,598	1000 - 10,000
Full blood count	3,600	3,815	500 - 150,000
Serum Electrolyte & Urea	5,021	5,418	1,100 - 18,000
Blood Culture	5,250	6,739	500 - 15,000
Blood transfusion	17,000	15,556	5,000 - 47,000

Table 3: Relationship between direct medical, direct non-medical and total cost of CHD and sociodemographic, clinical variables

Variable	Direct Medical Cost		Direct Non-Medical Cost		Total Cost	
	Median cost in naira (₦) (Range)	p- Value	Median cost in naira (₦) (Range)	p- Value	Median Cost in naira (₦) (Range)	p- Value
Age group						
< 1 years	42200 (250 - 44320)	0.685	2100 (300 - 40000)	0.487	40100 (250 - 463200)	0.538
1 - 5 years	46600(200 - 712000)		6000 (150 - 132000)		43000 (150 - 766000)	
6 - 10 years	46000(250 - 412000)		3500 (200 - 45000)		43500 (250 - 416800)	
>10 years	65875 (5500 - 95000)		3000 (300 - 21000)		32600 (400 - 116000)	
Socioeconomic class						
Lower	13775 (500 - 81000)	0.110	2400 (400 - 6000)	0.304	14675(500 - 30913)	0.196
Middle	54600 (250 - 712000)		2700 (150 - 132000)		50850 (150 - 766000)	
Upper	51500 (200 - 443200)		5000 (300 - 67200)		46600 (200- 463200)	
Mode of Payment						
Health Insurance	60500(1500- 285000)	0.793	6500 (300 - 67200)	0.336	49000 (1500-301000)	0.639
OOP	42200(200 - 712000)		4100 (150 - 132000)		40000 (150 - 766000)	
Duration of Cardiology clinic attendance						
< 1 year	42200(250 - 712000)	0.980	2900 (150 - 54000)	0.001*	40000(150 - 766000)	0.383
1 - 5 years	40000 (200 - 216500)		6000 (300 - 13200)		28600 (200 - 300500)	
6 - 10 years	81000 (250 - 412000)		6600 (200 - 45000)		95000 (450 - 416800)	
Effect of Payment						
CHE Household	127000 (12100-712000)	0.001*	8400 (300 - 132000)	0.001*	142400 (12700-766000)	0.001*
Non-CHE Household	13000 (200 - 197500)		2650 (150 - 67200)		15850 (150 - 209500)	
Co-Morbidity						
Present	65375 (200 - 443200)	0.025*	6850 (200 - 45000)	0.007*	63000 (150 - 463200)	0.016*
Absent	40000 (250 - 712000)		2250 (150 - 132000)		30300 (150 - 766000)	

Table 3: Relationship between direct medical, direct non-medical and total cost of CHD and sociodemographic, clinical variables ctd

Variable	Direct Medical Cost		Direct Non-Medical Cost		Total Cost	
	Median cost in naira (₦) (Range)	p- Value	Median cost in naira (₦) (Range)	p- Value	Median Cost in naira (₦) (Range)	p- Value
Co-morbidity_Heart Failure						
Yes	124600 (3500 - 443200)	0.001*	8100 (300 - 45000)	0.001*	122750 (2000 - 461200)	0.001*
No	25150 (200 - 712000)		2400 (150 - 132000)		23200 (150 - 760000)	
Co-morbidity_PHTN						
Yes	69700 (3500 - 412000)	0.308	7650 (1400 - 45000)	0.032*	75700 (8600 - 416800)	0.043*
No	44350 (200 - 712000)		3400 (150 - 13200)		40000 (150 - 766000)	
Co-morbidity_Downs						
Yes	40000 (200 - 412000)	0.644	6000 (200 - 40000)	0.279	45000 (200 - 416800)	0.740
No	49250 (250 - 712000)		3000 (150 - 132000)		43000 (150 - 766000)	
Type of Congenital Heart Disease						
Acyanotic	40000 (200 - 712000)	0.422	3400 (200 - 54000)	0.180	39200 (200 - 766000)	0.226
Cyanotic	56800 (250 - 334400)		6500 (150 - 132000)		63000 (150 - 382400)	

*Statistically significant

Note:

OOP: Out of Pocket

CHE: Catastrophic Health Expenditure

PHTN: Pulmonary Hypertension

Figures

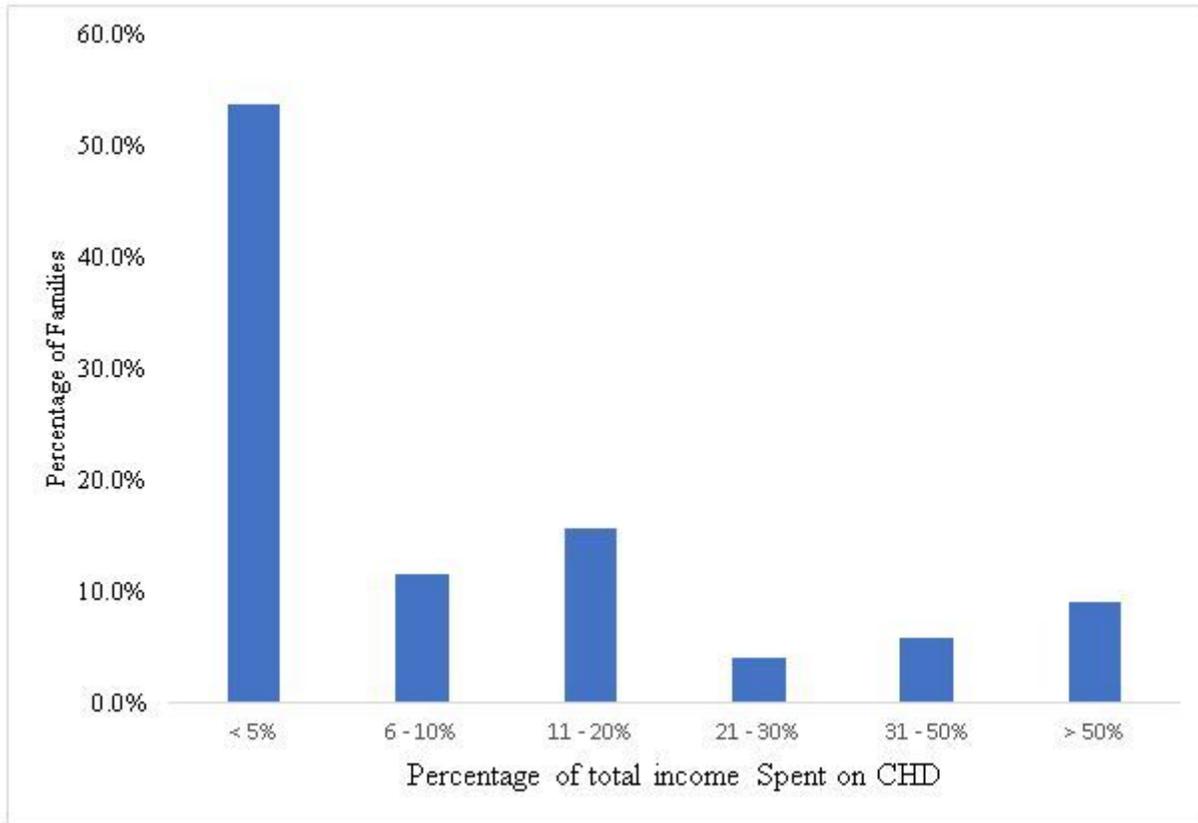


Figure 1

Proportion of total family income expended on care of children with congenital heart diseases